Patients with Pain Need Less Stigma, Not More

"Protection from and relief of pain and suffering are a fundamental feature of the human contract we make as parents, partners, children, family, friends, and community members, as well as a cardinal underpinning of the art and science of healing." With these words a blue-ribbon panel of clinicians, researchers and policymakers convened by the prestigious Institute of Medicine opened its landmark 2011 report, Relieving Pain in America. To prepare this report, the panel distilled a vast literature and developed new, detailed estimates of the economic cost of pain in the United States. The panel also reached out to the public, soliciting written or oral testimonies from more than 2,000 persons with pain, their family members and care providers. These testimonies eloquently convey the stigma experienced by nearly every patient with chronic pain:

- It has been hell. First, you have to find someone who believes you. (testimony #135)
- Doctors don’t recognize pain they cannot see or diagnose as a specific issue. (testimony #314)
- The stigma is one of the biggest barriers. I have been treated like a lowlife by medical people when I disclose that I have chronic pain and use opioids for it. (testimony #383)

Stigma—shaming and shunning—continues to befall patients with chronic pain, as do inequities in access to care. Tragically, people with the fewest resources to resist pain’s debilitating effects—minorities, the very young or very old, those with HIV, cancer, or substance abuse, the poor or homeless—are also marginalized by society. These “outsiders” have the least access to appropriate pain assessment and treatment. Even prosperous individuals often find their need for pain prevention or control is not addressed. Why is appropriate pain treatment so hard to deliver?

The reasons are complex but must be addressed now. First, humans are social animals who look to their peers to maintain the group’s cohesiveness and stability. This stability includes feeding and protecting the group from external assaults. Many packs or herds support their members immediately after injury. But with time, as they become less and less able to help feed or protect the group, they turn their backs on them, rejecting and expelling them. This inversion of the social contract towards persistently impaired members is seen in insect colonies through human communities. Brain scans of awake persons show similar areas turned on both during pain and with social rejection. Shame—hurtful rejection and isolation—is directed not only from the group towards the weakened individual; it also originates within that individual. People with chronic illness withdraw from their surrounding family, job or social contacts, lose self-esteem, energy and purpose, and even their prior sense of self. Being depressed is a risk factor per se for developing chronic pain, and vice versa. Failing to address depression or anxiety in patients with pain reduces the likelihood they will return to normal. But if and when their chronic pain is brought under control, people resume their roles in the family, in the workplace or school, and in society at large. No longer ashamed of themselves, they express profound gratitude to those who have “given them their life back” because social connectedness is at the core of a meaningful life.

In his Meditations, Marcus Aurelius wrote “When in pain, always be prompt to remind yourself that there is nothing shameful about it...Bear in mind also that, though we do not realize it, many other things which we find uncomfortable are, in fact, of the same nature as pain: feelings of lethargy, for example, or loss of appetite.” It is ironic that what has been common knowledge for millennia was ignored by the pain research community until “objective” images of the living brain in persons with pain allowed it to be quantified.

A second barrier is compassion fatigue among clinicians, including the well-described decline of empathy during medical and other health professional education. Without empathy and compassion, the medical encounter can slip into an instinctive default mode of stigmatizing or blaming. The literature on pain well documents a default attitude that pain is not a clinical concern (as used to be claimed for infants undergoing surgery due to their “immature” nervous systems, or third-degree burn victims due to their nerves being “burned off”). Morphine and other opioid analgesics were used minimally in patients with cancer owing to misguided fears of runaway dose escalation or substance abuse in dying patients. African-Americans slaves were described as less sensitive to or bothered by pain.

Given the longstanding neglect of pain by society, the Institute of Medicine’s 2011 report and its successor action plan, the National Pain Strategy, look to physician education and public education to achieve “a cultural transformation in the way pain is viewed and treated.” Medical educators have introduced courses and experiences designed to nurture and sustain empathy and
companion. Pioneering efforts emphasize the social and emotional dimensions of pain, transcending the traditional focus on microscale molecular and cellular processes. Identifying and addressing social, emotional, family, and environmental factors can impact the success of the clinical encounter of the patient with pain more effectively than time spent fruitlessly seeking a “pain generator,” e.g., in nonspecific low back pain. Practicing physicians find themselves under production pressure that forces them to choose between allocating the time needed for clinical care of patients with chronic pain, and meeting productivity standards expressed as average number of minutes per office visit. Intriguingly, a recent survey of pain physicians by leading pain educators found “compassionate care and empathy” was the highest-ranked pain topic. The article describing this survey concluded with the hope that “students will learn not only the necessary clinical knowledge but also be prepared to address the professional, personal, and ethical challenges that arise in caring for those with pain.”

That hope leads to the third and currently most damaging barrier now facing patients with chronic pain: the unprecedented rise in illegal diversion and abuse of opioids, often involving prescription painkillers, with pervasive societal consequences from addiction, crime, overdose, and death. Pros and cons of opioid therapy have been debated for decades, particularly for chronic noncancer pain. In the 1950s, John Bonica, one of the founders of the multispecialty chronic pain clinic, wrote “Many patients with chronic pain have conflicts that center around obtaining medications....The physician who is unaware of [pain’s] psychosocial dimensions will...become frustrated and wonder whether the patient is a drug addict or the psychological symptoms are the cause rather than the effect of the pain.” Now, hundreds of panels, committees, and task forces have been convened at local through national levels to deal with this “opioid crisis.” The medical community, particularly specialists in addiction or pain medicine, has provided education on managing pain through a combination of nondrug and drug therapies, including abuse-deterrent formulations of opioids. It has developed screening tools to indicate which patients are likely to do better or worse with opioid therapy for noncancer pain, and decision aids such as risk stratification questionnaires for opioid maintenance and guidance on urine drug testing for clinicians. It has advocated for the community availability of naloxone to treat opioid overdose, and for the use of prescription drug monitoring programs to avert multiple concurrent opioid prescriptions from different prescribers. Most importantly, it offers specialist pain consultation for patients whose primary care providers, general practitioners, surgeons, and others request it.

But amidst all this activity, the national conversation surrounding opioid therapy for chronic noncancer pain has become confusing, disjointed and, sadly, blameful for the majority of patients receiving opioids appropriately for chronic noncancer pain, and benefiting from such therapy—as well as the physicians who prescribe opioids. Both “pro” and “anti” camps generally agree that for the population receiving opioids chronically for noncancer pain, poorer functional outcomes and lower mental health scores are associated with higher doses and longer durations of opioid therapy. There is also general agreement that most patients prescribed opioids for chronic noncancer pain are not these problematic outliers. But there is disagreement on whether across-the-board limitations on access to opioids for chronic noncancer pain are, on balance, desirable or disingenuous. Of the alternatives to opioids, package inserts for NSAIDs have recently been rewritten to emphasize their safety warnings. Nondrug means of pain control, such as cognitive behavioral therapies, while valuable, are, like drug therapy for chronic pain or Lamaze breathing for labor pain, not sufficient or even suited for everyone. Insurers often limit payment for such services. Opioid dosage thresholds that trigger mandatory administrative actions ignore emerging insights into the genetic and epigenetic basis for individuals’ varied responsiveness to opioids. The framing of many such recommendations in terms of “equivalent” daily doses of morphine oversimplifies the wide range of reported conversion factors from one opioid to another, depending upon individual (gender, genetics), context (absolute dose level, duration of therapy, nature of pain), and even direction of transition between drugs. Practice guidelines put forth or proposed by different governmental agencies are not uniform, leaving prescribers uneasy that by prescribing opioids at any dose, to any patient, they place themselves in harm’s way. Indeed, current or proposed legislation, or administrative procedures enacted by many health systems, define a “high prescriber” of opioids simply in terms of falling in the top decile, quartile, or other mathematical value with no consideration given to clinical appropriateness. In Massachusetts, a recent law directs scrutiny towards any prescriber above the median, i.e., the top 50%!

In aggregate, the above activities appear to be resulting in an early downturn in the graph of total nationwide opioid prescribing across time. But like many other seeming solutions to a public health problem, they have produced unintended consequences—in this case, unleashing a torrent of blame and stigma directed towards all opioid prescriptions, prescribers, and patients. Other consequences include a lack of availability and/or prescribers able to meet the appropriate medical needs of their patients, including those with cancer pain. Some provide as their rationale the misinformation that simply being on an opioid chronically represents a form of addiction. Quoting flawed systematic reviews or opinion pieces, they misleadingly assert there is an absence of evidence to support opioids’ use for chronic noncancer pain. Previously emphasized distinctions between tolerance, physiological dependence, and addiction—distinctions that were the subject of much education aimed at reducing the stigma and shame experienced by patients—are once again being blurred. Increasing
numbers of legitimate patients are voicing personal narratives of long-term benefit from a chronic modest dose of an opioid, now finding such care terminated by policies based upon administrators’ interpretations of group statistics never meant to guide individual care.

What Must the Medical Community Do Now?

First, as physicians we must continue to support efforts to sustain our own compassion and empathy, often in the face of crushing workloads and compassion fatigue. Educational programs to improve wellness and avoid burnout are offered by the AMA and many of its constituent organizations. A companion AMA op-ed on the need to treat, not stigmatize, patients with substance abuse disorder reminds us that when tools such as prescription drug monitoring programs reveal aberrant behavior, “the real work is to understand why a patient is seeking medication from multiple prescribers or dispensers—and to offer a pathway for treatment or recovery.” The same may be said for using urine drug testing not simply as a “gotcha” to justify automatically terminating care for a patient with an aberrant result. We must ask whether we ourselves are falling into the default behavior of stigmatizing those with the greatest need for help.

Second, in providing patient-centered care, we must remember that to the vast majority of patients, chronic pain is not about drug-seeking. A recent Tufts survey of patients with chronic pain and their care providers, including health professionals and pain educators, took its cue from a CNN Twitter poll during Pope Francis’s 2015 visit to the United States, in which respondents were asked to describe him in three words. The pain poll asked respondents for three words they wanted the world to know about pain. The resulting “word cloud” is shown in Figure 1. It was clear that to this sample, pain meant “suffering,” “agony,” and “shame.” Some hopeful words were included such as “treatable” or “compassion”; the former was the closest anyone came to specifying a specific treatment. Absent from this cloud were the words “opioid” or “drug.” These results remind us that chronic pain involves the suffering and resilience of good but unfortunate people, the depth and complexity of whose experiences are not easily captured by purely quantitative data.

Third, while supporting efforts to curb inappropriate opioid prescribing and use, physicians must be mindful that undertreated pain in rich and poor countries alike is itself a crisis. Global estimates of the burden of all diseases identify low back pain as the greatest chronic health burden in developed countries; in the developing world, the greatest burdens involve conditions such as diabetes, depression, or war trauma whose deleterious effects on quality of life are directly linked to pain. Too many families have been shattered by opioid overdose or addiction—but also by ineffectively treated pain. Patients with pain are lightning rods for social blame and stigma. Inadequate pain relief increases disability, depression, suicidality, and collateral social burdens on families and the community. Institutionalization of stigma worsens patients’ sense of isolation and marginalization, undermines their resilience, and further diminishes their self-esteem and quality of life.

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