Treated like addicts

The crackdown on opioids has left patients suffering with chronic pain and stigmatized

By **Christopher Zara** Oct 24, 2016

Some days Cindy Laux feels like her skin is on fire. The scorching pain shoots down her legs like she just spilled hot coffee on her lap. Other days it feels like insects are crawling all over her. Laux has adhesive arachnoiditis, a rare, incurable condition often brought on as a result of multiple medical procedures. She's had four back surgeries since a work-related injury in the 1990s forced her into early retirement from her nursing career. Now the nerves in her lower spinal cord are clumped together, causing severe pain, urinary problems, and weakness in her legs. At only 53, she carries a cane at all times because she never knows when she's going to need it.

"My pain is out of control," Laux said recently from her home in Orange County, California. "I mean, I can stay alive, but my quality of life has dramatically decreased."

Laux has lived with debilitating chronic pain for more than 20 years, but for 15 of those years, she says, it was well managed with opioid painkillers. She took oxycodone and used a fentanyl patch. She could go hiking, travel to see her parents in Florida. That all changed beginning in 2011, when her doctor unexpectedly began prescribing her less and less with each visit. He gave no explanation aside from a vague reference to a rise in opioid-related overdoses. "Apparently, people are dying," she remembers him saying.

People *were* dying, and at an alarming rate. That year, the Centers for Disease Control and Prevention first used the term "epidemic" to describe the opioid crisis. Overdose deaths involving opioid painkillers had quadrupled over a span of 12 years, from 4,030 deaths in 1999 to 16,917 deaths in 2011. Emergency rooms were overwhelmed: Nationwide, they were treating as many as a thousand patients a day for prescription opioid misuse. As pill addiction — and, never far behind, heroin addiction — tore through communities and wrecked families, rehabs were taking in more patients than they could properly handle. One study of private insurance claims showed that diagnoses for opioid dependence shot up a staggering 3,203 percent between 2007 and 2014.

All of this paralleled a fourfold increase in the number of opioid painkillers being sold each year in the United States. While the drugs were once reserved mostly for short-term treatment of serious pain, like after an operation or a car accident, zealous marketing by pharmaceutical companies starting in the 1990s convinced more doctors to prescribe opioids for chronic conditions like arthritis and lower-back pain, ushering in an unprecedented era of overprescribing.

drug monitoring. In 2014, the Drug Enforcement Administration reclassified hydrocodone from a Schedule III drug to the more restrictive Schedule II category, and last month the Justice Department announced a far-reaching strategy to fight the opioid crisis with stepped-up enforcement measures, including prosecuting doctors who improperly prescribe painkillers. Meanwhile, President Obama is urging Congress to approve $1.1 billion in new funding to tackle the epidemic, largely by expanding access to addiction treatment.

In the five-plus years since the CDC issued that first warning, the opioid conversation has changed, a culture shift that culminated in March when the agency released sweeping new prescribing guidelines urging primary care doctors not to prescribe opioids for pain lasting longer than three months.

But for Cindy Laux and many chronic pain patients like her, the change has not been for the better. They feel like casualties in the opioid war, labeled as drug addicts and denied medication that they had relied on for years and sometimes decades. Today, Laux is still treated with opioids, but her dose has been so significantly reduced that she says she has lost her ability to function. She lives in a constant state of anxiety, terrified that further restrictions could prompt her doctor to cut her off completely.

“It’s a fear I live with every day,” Laux said.

The CDC insists it isn’t trying to create barriers to legitimate treatment. The new guidelines, the agency says, are the result of extensive input from experts and a thorough review of the available evidence. They don’t explicitly rule out opioids for chronic pain, but they do send a clear message that opioids should not be considered a first-line treatment. Debbie Dowell, a CDC senior medical advisor and the lead author of the guidelines, said the goal is to educate doctors and patients. “The guideline supports informed clinical decision-making in the context of the provider-patient relationship,” she said.

Still, the agency faced resistance from pain specialists, patients, and patient advocates who say the guidelines were based on scant data (studies examining the long-term effects of opioids are limited) and would only further stigmatize pain sufferers. The draft proposal attracted more than 4,300

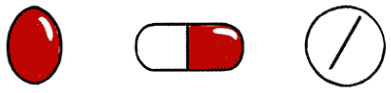
Alternatives do exist. For instance, the CDC says exercise therapy has been shown to improve physical function in some patients. Non-opioid medications, such as acetaminophen or ibuprofen, can be useful for conditions like arthritis and lower back pain, and some antidepressants and anticonvulsants are also effective.

But many patients say they have already tried every non-opioid option without success, or that they suffer from rare conditions that do not fit neatly into a one-size-fits-all treatment strategy. Over the years, Laux has tried every alternative treatment imaginable, from steroid injections to anti-inflammatories to biofeedback therapy. She even drank holy water from Lourdes, France. Her concern is that the CDC's guidelines, while not legally binding, will encourage a top-down approach to pain care that ignores the complex realities of individual patients.

Jacqueline Melzer, a 48-year-old chronic-pain patient, says she was told by her doctor in Reno, Nevada, earlier this year that he would no longer prescribe hydrocodone to treat her fibromyalgia and migraine pain. When she asked why, he said it was because there was no clinical evidence the medication she was taking for almost 20 years was helping her.

"I just looked at him and said, 'What am I supposed to do?" Melzer said.

It's a question many of the 25 million Americans who suffer with daily pain lasting longer than three months may be asking themselves. And for many of them, no one seems to have a good answer.



Two decades ago, it was pain — not pill addiction — that was being called an epidemic, with millions said to be suffering needlessly due to undertreatment by physicians. At least, that was the idea proffered by some physicians and

That same year, Purdue Pharma released OxyContin, a powerful painkiller sold as a slow-release pill, which the company aggressively marketed as a godsend for pain patients, often to doctors with little knowledge of abuse-disorder warning signs. OxyContin was a blockbuster, reaching sales of over $1 billion by the end of the decade. But it turned out the drug was also pretty easy to crush, snort, and inject for a high — and Purdue downplayed the risk of patients becoming addicted. In 2007, the company and its executives agreed to pay fines of $635 million for misleading the public.

That didn't stop big pharma from pushing opioids: A recent investigation by the Associated Press and the Center for Public Integrity found that drugmakers and opioid-friendly lobbyists spent $880 million from 2006 to 2015, often to fight state-level restrictions on the drugs. And sales of OxyContin and other opioids have continued to soar, with doctors writing some 259 million prescriptions for opioid pain medication in 2012, four times what they were in 1999. According to the CDC, those liberal prescribing habits played a key role in the dramatic rise in opioid painkiller-related deaths, which hit a record high of 18,893 in 2014.

Against this backdrop the agency released its prescribing guidelines, saying the risks associated with the drugs had to be weighed against their benefits. Those risks are much clearer now than they were in the 1990s. One study the CDC looked at showed that dependence among patients on opioid therapy was as high as 26 percent. Researchers also point to conditions like hyperalgesia, an increase in pain sensitivity, which can be brought on by long-term opioid use.

As for the benefits of long-term opioid therapy, the evidence is scarce. The CDC says few studies have rigorously assessed the benefits of the drugs for pain lasting longer than three months. Most randomized clinical trials the CDC reviewed lasted less than 12 weeks. Clearly more research is needed; in the meantime, the CDC says the urgency of the crisis required action.

But if the evidence doesn't support opioid treatment for long-term pain, why are so many chronic pain patients convinced they need the drugs to function? Andrew Kolodny, an influential substance-abuse expert and one of the

"The language that they'll use to describe how they think opioids are helping them is the exact same language my heroin-using patients use," Kolodny told me. "I've been treating opioid addiction for about 15 years. They use the same exact language: 'Doc, imagine what it feels like every morning — feeling like you've been hit in the chest with a baseball bat until you take your first dose.'"

In Kolodny's view, these patients are feeling better from opioids not because the medication is treating an underlying pain problem but because it's treating their withdrawal pain. And his view holds a lot of sway. He is the co-founder of an advocacy group called PROP, or Physicians for Responsible Opioid Prescribing, and a committee member of the Fed Up! coalition, which wants the federal government to commit more money to addiction treatment. He was also a member of the stakeholder review group that offered input to the CDC as it was crafting its guidelines.

Some pain patients I spoke with see Kolodny as Public Enemy No. 1 in a propaganda war, fueling an anti-opioid hysteria that favors hyperbole over nuance and glosses over the complexities of treating many painful conditions. One of those patients is Richard Oberg, a retired pathologist in Jackson, Tennessee, who says the current media narrative surrounding the opioid crisis is the most alarmist he's witnessed in 30 years of practicing medicine.

"I have never in my life seen an issue where the patient doesn't come first," Oberg told me. "They're confusing legitimate pain management with addiction. Those are completely separate venues."

Personable and charming with an affinity for colorful metaphors, Oberg speaks with a disarming Southern drawl that makes almost anything he says sound reasonable. But he's no neutral participant in the opioid debate. He suffers from psoriatic arthritis, a painful inflammatory condition that began to affect his ability to function when he was 39. He's now 62. For 18 years, he treated his pain with hydrocodone. (He also took biologics, which he said eventually stopped being effective.) As the condition worsened, he added low-dose methadone in 2011. It all ended three years later when the Medical Clinic of Jackson, where he received care, sent him a letter saying it would no longer prescribe long-term opioids, citing changes in Tennessee state guidelines.

"When they ceased it, it knocked the props out from under me, and that was it," Oberg said. "My time had come."

Eventually, he was able to find a local doctor who would prescribe hydrocodone, 50 milligrams a day, which he says is not enough to provide even a decent night's sleep.

Oberg's wife, Holly Clowers, suffers from Ehlers-Danlos syndrome, a painful connective tissue disorder, which she treats with buprenorphine. She says the bureaucratic and regulatory barriers to pain treatment have made receiving adequate care a demoralizing and physically taxing experience. In one case, she signed a treatment contract that required her to provide a urine sample whenever the clinic requested one, an experience she likened to being a prisoner.

In the current backlash to opioids, Clowers sees a callous prejudice against pain patients and a lack of compassion from physicians who see the sick as drug-seekers. "When you're sick, people assume you brought it on yourself, like it's your fault," she said. "We're not suggesting that there isn't a problem with addiction, but it shouldn't be causing chronic pain patients to be dumped across the nation."

Oberg and Clowers say the treatment roadblocks they've encountered are symptoms of a broken health care system. Their conditions are difficult, requiring time, effort, and careful management on the part of practitioners. Outpatient clinics have no place for them and primary care physicians, no time. Family doctors, as most of us know, tend to prefer an eight-minute visit — blood pressure, vitals, and maybe a few questions. Just as the "fifth vital sign" campaign encouraged physicians to prescribe opioids indiscriminately, the current crackdown on the drugs has provided a convenient excuse to abandon "complicated" patients, Oberg says, because the administrative burden is too high.

"We end up being the baby that gets thrown out with the bathwater," Oberg said. "It's just fine with them, because they don't want to see us anyway."

Kolodny doesn't waver when I mention the desperation I've heard from sufferers. "You've found a group of very vocal patients who are convinced that everyone is trying to take their opiates away from them," he said. "They believe that the CDC guidelines — that advocacy groups like mine — that what we're really after is stopping drug abusers, and that they're being made to pay the price. That's totally not what's going on. What's motivating us is an understanding that opioids are lousy drugs for chronic pain."

For consensus, Kolodny says to look to the country's leading pain clinics. The Cleveland Clinic, the Mayo Clinic, and the Washington University School of Medicine are a few of the institutions whose experts now say long-term opioid treatments are ineffective and risky.

But there are still pain specialists who disagree. One of them is Howard Fields, director of the Wheeler Center for the Neurobiology of Addiction at the University of California, San Francisco. Fields's interest in pain research dates back to his tour of duty in the Vietnam War, when he worked with a neurosurgeon who saw soldiers with painful nerve injuries. He worries that the current anti-opioid climate is being fueled not by evidence that opioids don't work for chronic pain but by a lack of evidence that they do. What's being lost in the debate, Fields says, is the old-fashioned practice of listening to patients, including those who say opioids are helping them. To simply write them off as addicts isn't fair.

"Why wouldn't you believe what the patient says?" he asked. "My attitude is, the patients pay you to make them feel better."

Meanwhile, there are signs that the era of overprescribing has peaked. A recent report from IMS Health, a health-data firm, found that 17 million fewer narcotic painkiller prescriptions were written in 2015 than the year before. But reducing prescriptions presents new quandaries: First, how do providers discern which pain patients could still benefit from long-term opioid therapy, even if it's only a small percentage? And second, what do we do with the estimated 9 million to 12 million American adults who are already taking opioids long-term?

want is for primary care doctors to just start firing these patients," he said. "That would be really bad. It's a problem that we need good solutions for."

Asked about that problem, the CDC's Debbie Dowell pointed out that the prescribing guidelines recommend tapering opioids slowly enough to minimize symptoms of withdrawal, a process that can take weeks or months. She agrees that simply whipping medications away from patients is inhumane. In fact, it's the only thing everyone seems to agree with. "It is almost never appropriate to abruptly stop prescribing opioid pain medication," Dowell said.

But as health care facilities change their policies and doctors grow more reluctant to prescribe, patients all over the country are reporting similar experiences of having their medication denied or reduced. In Tennessee, the Tennova Pain Management Center sent a letter to patients earlier this year, warning that it would no longer prescribe long-term opioids. It gave 30 days' notice. In Florida, pharmacies have been caught by local media refusing to fill legitimate opioid prescriptions after a statewide crackdown on "pill mills." In Oregon, Providence Health, a chain of 34 hospitals and more than 400 clinics, told the CDC that its pain specialists were seeing primary care doctors entirely discontinue prescribing opioids.

These instances may be rooted in good intentions, but they are riddled with side effects for patients who are slipping through the cracks. Some may turn to heroin or an illegal black-market for pills, a concern voiced by medical professionals and backed up by studies. Others may consider suicide. As the medical community grapples with how to reduce prescriptions without neglecting the needs of patients, disagreements about how to do that compassionately will continue to come up.

For Cindy Laux and patients like her, a sensible solution means the difference between agony and relief. Their pain is immediate, and whether you see them as patients or addicts, they are suffering in the same flawed system. If you're lucky enough not to live with chronic pain, and you don't know someone lost to addiction, this may feel distant and hypothetical. But that's only until it's not.

"Pain is everyone's problem," Laux said, "because everyone is eventually touched by pain."