"Complainers, malingerers and drug-seekers" — the stigma of living with chronic pain

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Early on an August morning in 1986, after a night without sleep, 16-year-old Keith Meldrum slid low on his seat and dozed off. He was alone, behind the wheel of a Plymouth Duster. The big, steel car missed a corner on the rural highway and rolled end over end. After the car came to a stop, Meldrum stumbled out and collapsed near the Duster's rear bumper.

"I was essentially torn through almost in half internally," said Meldrum.

He was 40 kilometres outside Prince George, British Columbia. Fortunately, two people in a car headed in the opposite direction had seen the accident. They flagged down another vehicle, this one carrying a crew of rail workers with a two-way radio.

An hour later, Meldrum arrived by ambulance at a trauma centre. Seven hours after that, a surgeon left an operating room and told two worried parents that their son would live. He was going to have problems. But he would live.

Long after the accident, after his wounds had healed, Meldrum would still visit the hospital several times a year, but only when the pain became unbearable. "It was a white-hot, stabbing, burning, blinding pain that would drive me to my knees and almost make me physically ill," said Meldrum. "There was nothing I could do to control it."

It's been more than 30 years now, but pain remains a part of Meldrum's life. Like many other Canadians struggling with chronic pain, Meldrum has at times faced challenges in a health care system that is better equipped to fix broken bodies than address suffering without obvious pathology.

"The most important thing you can hear is that someone believes you," said Meldrum. "You start to question your own sanity."

Keith Meldrum

Keith Meldrum has been living with chronic pain for more than three decades.

People with chronic pain are accustomed to feeling like medicine sees them as difficult patients. And many acknowledge that the perception is accurate. "There is no value in vilifying doctors or the medical system," said Meldrum. "We are complex cases. For chronic pain, there are many factors, including the psychosocial elements, and when you mix it all, it's a lot to deal with. Your doctor might not have any training in this area."

Another problem is that every patient with pain is different. There is no standard approach to help every individual manage their pain. "It's very subjective," said Maria Hudspith, executive director of Pain BC. "That makes it very complex, but it also makes it a very invalidated and stigmatized condition. When we think about medicine, we think about it being scientific and measurable. With a broken body part, we can see it. But for pain, when it becomes chronic, it's not that way."

According to Hudspith, pain is considered chronic if it persists longer than three months without any sign of a physical issue. Then it is no longer a problem of bone or tissue, but a sign that something

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is wrong with the nervous system. So the broken-anatomy model of health care no longer applies. Treating chronic pain well requires a fundamental shift in thinking away from viewing pain as a symptom of something else.

"I think of it as hardware and software," said Hudspith. "We are still talking about the hardware when it's the software that has a virus."

The stigma associated with having an invisible condition has been made worse by the ongoing opioid epidemic. The rise in misuse of opioids and the associated overdose deaths has made many patients with chronic pain feel under attack, and has made many doctors wary of prescribing opioids.

"Now the pendulum has swung so far in the other direction that we have physicians putting signs up in their waiting rooms saying they no longer prescribe narcotics," said Hudspith. "The problem I see in that pendulum swing is that nuance is being lost."

All the attention from governments, physicians and the media on the problems surrounding opioids has, however, helped to bring the subject of chronic pain out of the shadows. "I think the current opioid crisis is creating an opportunity for more education and awareness about the needs of people with pain," said Lynn Cooper, president of the Canadian Pain Coalition.

Employers are one group that often struggles to understand the complexities of chronic pain, according to Cooper, who suffered a back injury early in her career and has since been dealing with chronic pain. The assumption is generally that a worker who is injured, whether on the job or elsewhere, will eventually come back to work at full strength. But for employees who develop chronic pain, that isn't necessarily the case.

"People look at me and other injured workers and they assume that we are all fixed, and they can't understand why we are still having challenges," said Cooper. "It creates a lot of stigma. We are deemed as complainers, malingerers and drug-seekers."

Ironically, many people who have experienced pain themselves, but became pain-free after healing from disease or injury, also lack empathy for the plight of those whose pain doesn't fade. "People who do not live with persistent pain cannot understand what it's like," said Cooper. "Their only frame of reference is an acute pain episode, which might have been horrible for them at the time, but once the normal time of healing took place, or they took an intervention that worked, they go back to their lives as normal."

According to Dr. Fiona Campbell, a pediatric anesthesiologist and the president-elect of the Canadian Pain Society, the health care system also has much to learn about pain. "Pain is not at the forefront compared to other health problems. Pain is invisible and is often the byproduct of some medical illness, surgical procedure or trauma. There is no task that allows us to diagnosis it," said Campbell. "All in all, chronic pain is common, it's undertreated, and there is inadequate education and research."

Like others who work in the pain-management field, Campbell believes the complexities of chronic pain are lost on many people. Too much focus remains on the original problem that caused the pain, and not enough on the fact that, for some, the pain itself is the only remaining problem. "The pain pathways themselves become disorganized and they malfunction," said Campbell. "It's like a fire alarm going off even though the fire has been put out."

Treating patients with chronic pain will always be difficult, acknowledged Campbell. But there is much room for improvement in health care for dealing with this problem, and being suspicious of patients seeking relief from persistent pain doesn't help. "We have to begin with a focus of compassion and believing what patients tell us," said Campbell. "There will be some that exploit the system, but that is the exception rather than the rule."

Roger Collier, *CMAJ*