Bioethics expert calls for a national strategy to address chronic pain

Summer McGee publishes findings from the Pain Action Initiative: A National Strategy in the journal Pain Medicine

October 25, 2011 | Alissa Poh

Chronic pain affects one in four Americans and costs approximately \$650 billion each year in health care costs and lost productivity. Globally, one in eight people struggle with the problem.

"We're not talking about the occasional ache in someone's knee, but about debilitating, everyday pain that prevents a person from working, playing with his or her kids — all those things we regard as normal, good quality life," says Summer Johnson McGee, PhD. Chronic pain, she elaborates, is pain that persists for three to six months or longer. In other words, pain that should go away but doesn't.

"It's difficult to diagnose, because it's so subjective," Johnson McGee says. "I could say I'm in pain, and you could run every test in the world and find nothing that would indicate why." While certain conditions are associated with chronic pain — fibromyalgia, for one, or post-cancer bone pain — in many other instances, its cause is unknown.

The biggest misconception about chronic pain, according to Johnson McGee, is that it's a symptom of another condition and not a disease in its own right. "There's this notion that pain is to be endured, perhaps even valorized," she says. "I find that unacceptable, given today's medical advances. From a moral perspective, we have a responsibility to ameliorate chronic pain, even if we can't completely eradicate it."

Johnson McGee is an associate professor in the department of health policy and management at the University of Kansas Medical Center and writes regularly for the widely read blog.bioethics.net, one of Nature's "Top 50" science blogs. She also directs the graduate studies program at the Center for Practical Bioethics in Kansas City, Mo., where she is helping to run the Pain Action Initiative: A National Strategy (PAINS). This research and social advocacy project draws from a wide range of perspectives

including patients, healthcare professionals, legislators and representatives from law enforcement. Spearheaded by Myra Christopher, the Center for Practical Bioethics' president and CEO, PAINS began in 2010, when 110 representatives from 25 states met in five cities to define the ethics of diagnosing and treating chronic pain. Johnson McGee and her colleagues recently published findings from the first phase of the PAINS project in the journal *Pain Medicine*. Their paper highlights six primary themes from the regional meetings: patients' barriers in accessing pain care; a lack of quality pain care in the U.S.; the need for improved medical education and research on pain; myriad state and federal regulations that impede proper pain care; insufficient public awareness about the complex nature of chronic pain; and the good, bad, and ugly of opioid therapy.

On average, Johnson McGee says, a chronic pain patient gets ping-ponged between seven different providers before receiving a diagnosis, much less treatment. "Doctors seldom go beyond knee-jerk responses like 'Well, let's get you a painkiller,' or 'We'll give you an epidural in your spine' to ask questions like 'How is it impacting your daily life? What could you do before that you can't now?'," she says. "That would take more time than the average physician is able or willing to spare."

Unsurprisingly, these patients become disenfranchised with the healthcare system. Meanwhile, healthcare providers are equally frustrated by constant calls for prescription refills. The line between alleviating honest-to-goodness pain and misusing medications is not clear.

"Both patients and physicians are often put in very difficult positions," Johnson McGee says. "So while trust and integrity should be at the heart of every provider-patient relationship, these elements may be even more necessary in chronic pain, to overcome this culture of fear and suspicion and enable people to access the treatment they need."

Changing the reimbursement structure so chronic pain gets its own diagnosis codes, she adds, would provide fresh incentive for doctors to spend more time getting to the root of their their patients' pain.

The medical education system also needs to be revamped, Johnson McGee and colleagues note, so chronic pain management moves beyond palliative care and anesthesiology, and students receive training in this area early on.

"We can't afford to wait," she says. "This generation of physicians needs to realize that they may have been trained one way, but what we now know is different — as such, they should adapt and start treating pain as a disease, not a symptom." They advocate having the chronic pain curriculum evolve into an interdisciplinary model of care, where opioids are but one form of therapy and other modalities, including behavioral and physical, receive equal consideration.

Johnson McGee and colleagues would also like to see an increase in federal funding for pain research. Currently, the PAINS project is funded by the Lance Armstrong Foundation, the Rx Action Alliance, and Purdue Pharmaceuticals. 'The main monetary source for many of us working on chronic

pain is the pharmaceutical industry," Johnson McGee says. "I believe you can receive pharma's support and do good, intellectually honest research — but we'd still prefer to not be so reliant on private funds."

PAINS has established that stakeholders across the U.S. are enthusiastic about developing a strategic national plan to improve the diagnosis and treatment of chronic pain, Johnson McGee says. However, even though numerous individuals and organizations have been working on specific focus areas of chronic pain, these efforts still lack coherence and collaboration, with many entities often working at cross purposes.

"Getting the various groups and people on the same page will be a very big task, but it's necessary for the societal change we seek," Johnson McGee says. "What really surprised us was finding that when comprehensive management of chronic pain was framed as a moral and ethical issue, everyone — regardless of organization, affiliation, or ideology — could get behind it. It was a lot less threatening than framing it in terms of health policy, insurance reform and such."

The next phase of the PAINS project will be to break down existing "silos" within the pain community so the proposed national coalition moves beyond the planning stages and becomes reality.

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