Bridging the Pain Communication Gap

Cancer patients and providers share tips on discussing pain to inform symptoms and treatments, including for Black women with breast cancer.

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Communicating pain presents a challenge for patients and providers. Patients have their own individual experience of pain, while providers receive widely variable inputs or explanations.

This information gap creates issues with diagnosis, treatment and helping patients navigate treatment's collateral damage. The first step in bridging that information gap often involves a universal pain scale that asks patients to rate their pain level from 0 to 10.

The first time that Hanna Hunter, MD, asked Pam Stoeffler to assign her pain a number from 0 to 10, Stoeffler said: "Is there a 12?"

Stoeffler is no stranger to both acute and chronic pain. She has Gardner's syndrome, which causes intestinal polyps and soft and hard tumor growth. In 2020, she got sepsis while visiting her extended family and wound up in the hospital. In 2019, she had surgery for rectal cancer. Before that, she had breast cancer.

"My pain can go from 0 to 12 just like that," she said.

A year ago, in 2022, Stoeffler went to see Hunter, medical director for Fred Hutchinson Cancer Center's cancer rehabilitation and rehabilitation medicine, because she was experiencing pain in her left hip.

After examining her hip and ordering an MRI, Hunter suggested specific exercises and stretches that made Stoeffler's hip pain easier to deal with. "I work hard with all my doctors to negotiate the pain so I feel better," she said. "I have incredible providers who always listen."

Listening is one thing; understanding what the pain feels like is another. That's why Stoeffler tries to be as specific as possible and leans heavily on comparisons: the pain feels better or worse than it did last week, say, or last month.

"I'll say the pain is driving me crazy all the time, or it bothers me most at night, or I can bike five minutes more on the Peloton than I used to," she said.

Her friends have picked up on this tactic and use it to encourage Stoeffler. Her walking buddies

will say, “You’re walking longer now or going up hills that you didn’t used to attempt.”

Those friends are part of a small circle of people who know the extent of Stoeffler’s discomfort. “I censor myself a lot,” she said. “It makes people uncomfortable to hear about pain. They don’t know what to say. I don’t want people to think it’s going to slow me down; I want people to think the opposite.”

Hunter uses the standard pain scale to assess patients’ pain, but she finds it to be an imperfect tool. “The pain scales are so tough,” she said. “Pain can be severe or mild, but it can still impact what patients need to do from day to day. As a rehab doctor, I end up focusing on impact: what makes the pain worse, what makes it better and how does it limit you?”

Even something like nerve pain in fingertips can prove consequential.

“If your career depends on fine motor skills, it’s a big deal,” Hunter said. “Asking patients what their pain prevents them from doing is the bigger question, and it also helps me figure out how to treat it. With back pain, if it’s a 0 at rest, but it limits them from walking, we have to tease that out.”

During her training, Hunter learned an acronym, CLODIERS, that she still relies on. It stands for characteristics, location, onset, duration, intensity, exacerbating factors, relieving factors and other symptoms like numbness or weakness. CLODIERS helps Hunter look beyond the pain scale to reach a more holistic assessment of what a patient is experiencing.

“Getting a number is just getting the intensity,” Hunter said. “It doesn’t paint a full picture.”

Hunter works with the specialists in Fred Hutch’s Pain Clinic to manage patients’ pain. She treats patients who tend to have more chronic, long-term pain related to musculoskeletal side effects, such as post-mastectomy pain, while the pain specialists see patients who have pain from current cancer treatment.

As one of two physicians plus a team of nurses and pharmacists who comprise the pain clinic, Dr. Margaret Hsu helps support patients whose pain needs attention beyond what their oncology team offers.

“Some oncologists are more comfortable with treating pain,” she said. But the pain specialists offer a level of expertise that transcends what oncology can provide, especially when it comes to addressing what’s called “complex pain” — a patient with a history of chronic pain, for example, who then gets a cancer diagnosis, or a patient with cancer and a history of substance abuse.

“We are more comfortable prescribing and making sure patients are closely supported,” Hsu said.

Pain can affect a patient’s mood, sleep and appetite. “Many patients tell us their pain is worse when they’re stressed or anxious, so we make sure we assess them through a wide lens and see how pain affects their quality of life and their goals, what do they want to be able to do,” said Hsu.

A treatment plan may include being seen at Fred Hutch's Integrative Medicine program, which offers acupuncture and mindfulness, as well as Hunter's cancer rehab clinic and psychiatry services. "We want them to be able to do things they love," she said.

As with Hunter, Hsu recognizes the limitations of the pain scale, which prompts her to also pay close attention to nonverbal cues — how a patient sits or moves around the exam room.

"I always ask patients about their pain numbers, but I'm aware it's completely subjective," she said. "Sometimes I ask what number is your goal? At what number can you walk to the store or make food for yourself?"

Intrinsic Fear of Opioids

The opioid crisis has made pain management more challenging. Many patients opt to avoid prescribed opioids, hesitant to take powerful pain medications that can relieve their pain because of the societal stigma surrounding the drugs and their highly addictive potential. However, Hsu notes that the rates of new addiction to pain medications during cancer treatment are low, with the benefits outweighing the risks for the majority of patients.

Providers closely monitor patients to whom they've prescribed opioids for relief of cancer-related pain. "We want to make sure the patient's pain is adequately treated, then we work with them to see if we can bring their doses down to the lowest effective dose while focusing on maintaining their function and quality of life," Hsu said.

Medical marijuana is also used by patients and providers to help manage cancer-related pain.

Dr. Steven Pergam, medical director of infection prevention at Fred Hutch, has conducted research into the use of marijuana in cancer care. Inequitable distribution aside, not everyone tolerates opioids, which also can have unpleasant side effects including constipation, cloudy thinking and dizziness.

"Opiates provide wonderful pain control, but we're in a generation where opiate addiction is no longer hidden in the background," he said. "It's made all of us rethink how we prescribe these drugs, but we also need to treat patients' pain."

Not long ago, Pergam was in the hospital with a knee issue, and declined opioids for pain relief. "I was nervous to take opiates because I was worried about having some kind of reaction," he said. "It was an intrinsic fear."

Some patients see marijuana as a natural substance for pain relief. "Data suggests there may be some benefits," said Pergam, who notes there hasn't been a high-quality randomized clinical trial because of restrictions on marijuana use. "That's changing state by state, with states that have more recreational access having more opportunity to do studies in this space."

Pergam's research assessed patient interest in using marijuana and found that up to 25% of patients try it and opt to use it during cancer treatment. "They say it helps them sleep and decreases pain," he said. A study from Michigan found that patients who use marijuana use less opiates than those who relied solely on opiates for pain relief. "Marijuana could offer an alternate way to provide pain relief," he said.

How to Effectively Communicate Your Pain

- Be specific. What does it feel like? Where does it hurt and when?
- Use comparisons. Is it better or worse than it was last week?
- Quantify. Is it worse at a particular time of day? Do certain activities increase the pain?
- Assess impact. Explain how it is affecting your behavior or mood and your ability to live your life.

As an infectious disease doctor, Pergam began looking into marijuana's role in cancer care in 2018 after fielding questions from both patients and providers about whether it was safe to use. A research project that tested leftover urine samples confirmed that 25% of patients were using the drug.

"Cannabis is like any other dying leaf," said Pergam. "When it sits in a container, it gets moldy. Mold when inhaled can increase the risk of patients getting fungal pneumonias. There's never been a good study looking at cancer patients and this, but I worry about patients with low neutrophil counts introducing infection to their lungs."

Pergam is interested in the potential dangers, especially as they relate to drug delivery. There are questions about whether marijuana can affect chemotherapy's uptake, with one paper suggesting that patients who smoke marijuana don't have as robust a response to certain kinds of chemo.

"In the pharmaceutical space, if I'm giving someone 5 mg of something, I know what I'm delivering and can always deliver the same dose," he said. "With marijuana, I might get Girl Scout Cookie [a specific strain of marijuana] at two purveyors and the THC component may not be the same, so it's harder to gauge."

Just as a person's experience of pain is a challenge to communicate because there's so much variability, the same holds true for marijuana dosing. Smoking marijuana is different than consuming edibles, for example.

“Patients often experiment to figure out how much to use,” said Pergam. “Can that cause confusion or contribute to a risk for falls? Can there be drug interactions?”

There are also complementary approaches to pain.

As medical director of Fred Hutch’s Integrative Medicine Program, Dr. Heather Greenlee regularly sees patients in pain who want to avoid traditional pain medications. Fred Hutch is currently running a clinical trial testing the use of acupuncture to reduce pain and the need for opioid prescriptions. Read more about curbing joint pain with acupuncture.

Greenlee emphasizes the value of incorporating mind-body therapies that take a non-pharmacologic approach to pain relief and don’t interfere with treatment, such as mindfulness, progressive relaxation and guided imagery. These modalities can also help with communication of pain since one benefit of the mind-body connection is increased awareness.

“Mind-body medicine can help reduce the severity of the pain that people experience, help them manage it and decrease the stress response around pain as well,” said Greenlee.

Not all patients are interested in integrative therapies, but for those who are curious, Greenlee and her team serve as a bridge between those patients and the integrative medicine group’s conventionally trained colleagues.

“Pain can be difficult to understand from a conventional oncology perspective,” said Greenlee. “Conventional oncology often turns to pharmacological pain relief, but non-pharmacological approaches can also be effective at managing pain. We help patients explore other healing modalities that fall within the worldview of a lot of patients and can be empowering for them.”

A Race-Based Experience of Pain Relief

Various cultures have different ways of talking about pain, and the words and phrases used to describe pain vary from language to language, says Greenlee.

“Patients come to us from different cultural traditions or backgrounds or different parts of the world,” she said. “They seek a holistic approach to health and wellness.”

Greenlee says that in her clinical experience, some Latinas express pain differently than non-Latinx white women and tend to tell providers that they are experiencing higher levels of pain.

“We know that in clinic, people from different racial and ethnic groups talk about the experience of pain differently,” she said. “Socioeconomic stressors are known to increase how people experience pain. Unfortunately, there is a history in medicine that people from different racial and ethnic groups aren’t listened to in the same way by all clinicians.”

Bridgette Hempstead knows all about that.

She started the cancer support group Cierra Sisters 27 years ago to empower Black women facing breast cancer after she was diagnosed with the disease on her 35th birthday. A doctor incorrectly told her that she didn't need a mammogram because breast cancer doesn't affect the Black community; Cierra Sisters was born three days later as a resource for patients, survivors, caregivers and supporters in the Puget Sound area.

Hempstead's advocacy has grown to include a focus on raising awareness that Black women's pain is not taken seriously enough.

"Stage 4 patients are told to take Tylenol and are being refused medications that could help their situation," said Hempstead. "But white patients are getting oxycodone and other narcotics that will stop pain without any questions. They're being asked, 'Do you need anything else?'"

She traces this dynamic to a medical culture that she says has historically treated Black patients as "guinea pigs, not as human, to the point that they're experimented on without any pain meds. This history has continued into 2023."

In response, Hempstead is creating the Cierra Sisters Antiracism Oncology Project, partnering with Fred Hutch to create ways to address racism in cancer care. She's interviewing doctors, researchers and administrators along with survivors and caregivers to document the problems and outline potential solutions.

Funded by the nonprofit Center for Health Care Strategies, the goal is to assemble a toolkit to share locally and globally to help cancer centers understand how they need to change their approach to care for Black women.

"The racism is real," she said, "and it's creating disparities, which is creating a high death rate. Black people need their pain to be treated as equal."

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