The Feather and the Knife: Navigating Life With Chronic Pain

Chronic pain is a fact of life for far too many people living with HIV. But new research aims to address it at its core.

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For Jesús Guillén, pain is a feather touch and a constant companion. To illustrate, Guillén, who has been living with HIV since 1985, moves one elegant hand, bending at the wrist to mimic running a feather gently along skin.

“I just start doing this over and over and over,” he says. “I tell people, ‘This is a feather. But what do you feel if I keep doing this for 30 minutes, or for an hour?’”

Usually, folks push him away, irritated at the sensation. That’s one of the ways Guillén describes the chronic pain that sometimes keeps him in bed until noon and can make every step hurt. But that’s not the only way he describes it. There’s the feeling of a nail or a thorn from a rose pressed nonstop against skin. And then, there’s the pain that wakes him up in the middle of the night and consumes his thoughts, like a knife stabbing him over and over again. For Guillén, chronic pain is a lack of sensation, then, all at once, too much sensation—and a sensation he can’t escape.

“It never stops. [People with chronic pain] don’t get used to it, but we manage somehow,” he says. “We still want to experience life in some way.”

Guillén is far from alone. Studies have found that between 25% and 85% of people living with HIV experience chronic pain, compared with estimates of 11% to 20% of the general population. Often, this is neuropathic pain—pain that starts in the brain but is usually experienced as numbness, tingling, burning or stabbing in the limbs, hands and feet.

Despite the high rates of pain, some research suggests that people living with HIV are less likely to be prescribed opioid pain treatment than their HIV-negative peers. The additional challenge of coexisting substance use disorders can render even that form of pain relief elusive for some people with HIV. But the opioid epidemic has led to new research on pain and how to address it at its core, including specifically for people living with HIV.

What We Know About Pain and HIV

Jessica Robinson-Papp, MD, had just come off a general medicine internship at St. Vincent’s hospital in New York City, where she fell in love with working with HIV-positive people, when she began training in neurology. Luckily for her, she was able to combine her passions. Today, she's a clinical neurologist at New York City's Mount Sinai Hospital, serving people with HIV who have a variety of pain syndromes.

The more people with HIV she saw, the more Robinson-Papp realized that peripheral neuropathy was usually just one of a litany of pain complaints her patients had.

"You'll start talking about neuropathic pain," she says. "And then they'll say, 'Oh, but then, there's back pain,' and 'There's pain radiating down,' and 'There's pain over here,' and 'Then, there are headaches.'"

What she's learned, and what the science of pain in general has revealed, is that there is no one cause of pain, or, if there is, science hasn't discovered it yet. It's not even clear whether people living with HIV really experience more pain than people without HIV, Robinson-Papp says.

"We don't even really know that," she says. "Understanding the [source] of pain is very much in its infancy."

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What researchers do know is that pain is more likely a syndrome—a constellation of symptoms—than one disease with a single cause that can be cured. In fact, each kind of pain could have a different cause.

For instance, neuropathy is often a side effect of older HIV medications or chemotherapy for AIDS-defining illnesses. It could also be due to accelerated aging in people with HIV. Then there's degenerative joint disease—that is, joint pain due to osteoarthritis or avascular necrosis, which often necessitate joint replacements. For people who menstruate, menopause can come with its own kinds of pain. HIV-associated chronic inflammation is another "likely contributor" to pain, Robinson-Papp says.

What's more, people with one pain syndrome, such as HIV-associated peripheral neuropathy, are more likely to have another, like migraines or joint pain from osteoarthritis—or even multiple other pain syndromes. Scientists don't know why that is either, says Robinson-Papp.

Plus, some factors may amplify one's perception of pain. For instance, it's possible that some HIV viral proteins themselves may enhance pain. Pain is also associated with other health conditions, such as depression, anxiety or posttraumatic stress disorder, most of which can be part of what's known as AIDS Survivor Syndrome, a cluster of symptoms resulting from trauma endured during the early years of the epidemic.

Then there are factors that can make it easier to focus on pain, like the social isolation that can accompany aging. Moreover, certain behaviors, such as lack of exercise, can increase pain, and conditions such as insomnia or drug misuse or addiction (which can be an attempt to self-medicate) can complicate how individuals cope with pain.

All of this can impact the ability to take HIV meds as prescribed, which can deprive people with uncontrolled pain of the health benefits of having an undetectable viral load.

So when Robinson-Papp talks to patients about options to alleviate pain, the first step is to see if there's a physical reason for it, like diabetes, autoimmune diseases, infections such as hepatitis B or C or malnutrition associated with alcoholism.

But once Robinson-Papp has helped patients address those problems, there are only a few proven solutions she can offer people to help manage their pain or at least cope with it. These include physical therapy, massage, acupuncture, mindfulness-based stress reduction, cognitive behavioral therapy, exercise, non-opioid pain relievers and cortisone injections (for joint pain). Some data show that cannabis and capsaicin (derived from chili peppers) alleviated some pain in people with HIV, according to a systematic review published in a recent special issue of the journal AIDS Care on the topic of HIV and chronic pain that Robinson-Papp coedited. But the quality of the data were low, and more work is needed to confirm their effectiveness, researchers wrote.

That leaves one last option. "Sometimes people are on opioids," she says. "That's a fact of life."

Guillén knows this all too well. It's taken years to find the right mix of meds, one that keeps the pain to a manageable level but doesn't wallop him with brain fog or fatigue. He rattles off the list of meds he's tried for pain: Cymbalta, morphine, medicines for depression, even schizophrenia drugs.

For five years, he's been on a regimen that works for him: a base of 20 milligrams of OxyContin (oxycodone hydrochloride) twice a day, with Norco (a combination of hydrocodone and acetaminophen) as needed but no more than one pill every four hours. He augments these with over-the-counter pain patches, hot and cold compresses, a device to deliver nerve stimulation to muscles and massagers.

"Temperature, movement, vibration—these are all different elements that affect whatever you're feeling," he says. "But this is not a formula or a recipe. It is a lot of work, sadly, to find whatever works for you."

Opioid Epidemic Leads to Innovations

Science's understanding of HIV and pain may be about to change, however. In the HIV and chronic pain issue of AIDS Care, a global task force of HIV experts began to lay out a research agenda for studying pain in people with HIV. (Their preference: Start with what causes it.) The issue includes new data showing that many HIV-positive people can't separate their chronic pain from their experience of having the virus.

The HIV Global Pain Task Force, of which Robinson-Papp is a member, is now soliciting recommendations for the HIV pain research agenda from people living with HIV.

Another effort is more wide-ranging. The National Institutes of Health (NIH) launched the Helping to End Addiction Long-term (HEAL) Initiative in 2018 and has so far funded it with $1.5 billion to back experimental research and the development of medical devices that might treat opioid use disorder or address or prevent pain.

The funding also supports the Pain Management Effectiveness Research Network, which is testing existing non-opioid drugs against pain, and the Pragmatic and Implementation Studies for the Management of Pain to Reduce Opioid Prescribing as well as new research paths for interventions that could treat pain without requiring opioids.

That’s where Marco Loggia, PhD, associate director of Massachusetts General Hospital’s Center for Integrative Pain NeuroImaging, comes in.

Loggia isn’t an HIV researcher. But he has dedicated his career to studying what pain of all sorts looks like in the brain using PET and MRI scans.

Neuroinflammation is what brought him to HIV. Chronic HIV infection can lead to persistent immune activation and inflammation even among people on effective antiretroviral treatment who have an undetectable viral load.

Loggia’s lab was the first to show that in people with chronic pain a protein in the brain called translocator protein (TSPO) is present in unusually high numbers in the thalamus, the part of the brain that perceives pain and other stimuli. If his theory is correct and the presence of TSPO in people with chronic pain isn’t just a coincidence but actually an objective marker of how much pain people are in, lowering TSPO might also reduce how much pain a person feels, without the need for opioids. Drugmakers could then develop medications that target and reduce TSPO and therefore reduce the pain itself.

“HIV is a perfect storm” of neuroinflammation, he says. “We wanted to know—above and beyond the inflammation associated with the virus—why some people with HIV have pain and some don’t.”

In short, if all people with HIV have neuroinflammation, why don’t they all also have pain? And does neuroinflammation look different in the brains of HIV-positive and HIV-negative people with chronic pain?

Loggia’s current study is recruiting participants in the Boston area to be part of an imaging study to look at just this. It divides participants into three categories: 30 people living with HIV without chronic pain, 30 people with HIV and chronic pain who engaged in opioid pain management and 30 people with HIV with chronic pain not taking opioids. That’s because of another complication of opioid use: Scientists think ongoing opioid use could actually increase inflammation, and maybe TSPO, in the brain.

The HEAL Initiative gives Robinson-Papp hope for the future of pain treatment for people living with HIV.

“The HEAL Initiative has really brought together the addiction world and the pain world, which I think is extraordinarily beneficial, particularly for the pain world, because there are ways addiction medicine conceptualizes care that would be really lovely for us as well,” she says, noting addiction care’s focus on harm reduction. “You have to think about the whole person—where they live, what the context of their pain is.”

Jesús GuillénAngela DeCenzo

Reclaiming Joy

One of Guillén’s early memories as a child was dancing with his aunts. One aunt would take him by the hand, and another aunt would grab his sister. They would teach the kids salsa and other dances. When Guillén remembers it, he beams with adoration for his aunts, one of whom recently died.

In the years since, his experience in his body is, like pain, never just one thing. The breathtaking rush of a first kiss and first touch with another man linger with memories of the burning under his skin that came with his HIV diagnosis. The horror of the feel of bald patches on his scalp from the stress of being closeted and living with HIV in 1985 coexist with the youthful energy of nights spent at discos, dancing until dawn. There’s the mix of adrenaline and the great vibration in his chest from standing in front of a crowd and singing. Now, at 60, in chronic pain and with a hip replacement, Guillén is proud of the fact that these days, when he does dance, he can still break it down all the way to the ground.

Sometimes, when every step on the sidewalk feels like stabbing, he imagines he’s walking on a bed of Jell-O. It takes him out of his current body, this painful body that nevertheless he loves.

He can still access the joy he felt dancing as a child. It will cost him in energy and recovery later, but for five or 10 minutes, his feet move in that familiar way, in concert with his shoulders, hips leading, weight shifting from balls of feet to heels, shoulders shifting to compensate. For those minutes, he is that child again, dancing in the kitchen with his aunt.

Some days, that’s just a fantasy. But he can escape into that memory and know what it’s been like to be a whole person in a currently painful body.

“Even if we’re sitting down, we can have those wonderful memories of movement,” he says, as his hands come up in front of his chest and his shoulders shimmy. “And even with just the hands, or the hands right here, we are in our brains really doing the twist. And it might help.”

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http://beta.docker.poz.com/article/feather-knife-navigating-life-chronic-pain