Ouch! Stop the Pain

Patients don’t want to talk about it. Doctors don’t want to hear about it. What’s going on?

June 1, 1999 By Stephen Cornell

Rick Otterbein felt like he’d been living the same doctor’s appointment over and over. The Dearborn, Michigan, PWA had been complaining for months about lower back pain. He had trouble sleeping. He couldn’t carry anything heavy or stay on his feet for long. He had to cut back his work load. But each time Otterbein asked for a pain reliever, he was turned down. After tests could not find the cause of what was wrong, his doctor told him to go home, take some Valium (an anti-anxiety drug that also acts as a muscle relaxant) and get a few days of bed rest. Otterbein knew that wasn’t the answer. “When I took Valium, it gave me a loopy, dazed feeling,” he says. “It made the pain a little easier to ignore, but I wanted something to take the pain away.”

Otterbein’s doctor didn’t consider prescription pain meds an option, since years earlier Otterbein had been a substance user. “My doctor said that if he gave me a painkiller, it would just get me addicted,” Otterbein says, “and he didn’t want to string me out on something.”

His feeling of *déjà vu* continued because two years earlier, a different doctor refused to prescribe anything stronger than ibuprofen for severe shoulder pain that immobilized his arm. Otterbein says that many PWAs in his support group have also been denied adequate pain medications because of a substance-use history. “Neither of my doctors took my pain seriously,” Otterbein says. “I was just looking for something to improve my comfort level, since I’m an active person. Maybe because I’m a PWA I’m not supposed to be busy.”

Research shows that many, if not most, PWAs experience pain, and that HIV-related pain increases with disease progression. Participants in one study experienced an average of 2.7 pains, distributed among various body parts, at the time of their interviews. Causes included infections, cancers, nerve damage, diarrhea and medication side effects. Another study found that on a standard zero-to-10 scale, the pain of PWAs averages five or more—moderate to severe.

Yet doctors often not only downplay but inadequately treat pain, according to numerous studies. Across disease lines, children, people of color and the poor tend to receive inadequate treatment, and oncologists notoriously undertreat cancer pain. PWAs may be the most poorly treated of all. A 1997 multicenter study in France found that doctors underestimated pain in 52 percent of PWAs. Among those who had moderate or severe pain, only 43 percent were treated.

The situation in the United States may be worse. William Breitbart, MD, a leading HIV pain specialist at Memorial Sloan-Kettering Cancer Center in New York City, says that U.S. studies have estimated that doctors provide adequate pain management for only 15 percent of PWAs with pain. For former substance users with HIV, that figure dropped below 8 percent.

Yet according to Gayle Newshan, a nurse practitioner at St. Vincent's Hospital in New York City and author of several studies on HIV-related pain, 90 percent of the pain PWAs suffer can be relieved using established nonsedative therapies. "It's rare for any patient to have such severe, intractable pain that only sedation can keep them comfortable," Breitbart says. Even physicians without sophisticated pain-management training, he notes, can provide relief for patients with HIV by following existing guidelines (with individual adjustments, if needed, for former drug users). Medications of increasing potency—from nonsteroidal anti-inflammatory drugs (NSAIDs) to opiates—can be used to treat pain of different intensities; several alternative treatments, slowly gaining more mainstream acceptance (but still only occasionally reimbursed) also have evidence of effectiveness (see "How to Spell R-e-l-i-e-f" below).

Although strong opiates such as codeine and morphine constitute the single most important class of drugs for treating moderate to severe pain, their use is shrouded in ignorance and misinformation. Extensive research shows that hardly anyone becomes addicted from proper use of opiate painkillers. Yet fear of addiction can be a major obstacle to effective pain relief for PWAs, especially former or current substance users. One study found that among HIV positive patients with similar pain levels, present and former injection drug users (IDUs) were more likely than non-IDUs to receive inadequate pain treatment. According to the study's authors, "Physicians' concern that patients may abuse prescription medications undermines the trust in the doctor-patient relationship" and fuels doctors' skepticism of patients' complaints. The problem may grow along with the rate of new HIV infections among people who have been IDUs, a figure currently estimated at 50 percent. Although no one knows the relapse rates for IDUs who are prescribed opiates to manage pain, the risk is generally believed to be slightly higher than for others. But experts agree that even if there is a small risk of relapse, present and former users deserve pain relief.

Stereotyping by physicians limits access to pain meds for an even broader swath of the HIV community. As St. Vincent's Newshan wrote in one study report, "Pain management is often complicated by the negative attitudes of health professionals toward PWAs," noting widespread social stigma against not only present and former substance users but also against gay and bisexual men and poor women of color. Another study found that women with AIDS are twice as likely as men to be undertreated for pain.

Part of the problem can be traced to the U.S. government's War on Drugs. "In this era, we've told people to say no to drugs," says B. Elliot Cole, MD, former president of the American Academy of Pain Management. "We haven't qualified that to illicit drugs." One important victim of this approach has been medical marijuana—illegal in all but seven states. Yet a recent report by the federal Institute of Medicine found pot to be useful for managing pain, among other conditions (see "Sense and Sinsemilla").

A direct result of this antidrug policy is a requirement by 16 states that a state agency be notified each time a doctor prescribes certain narcotics. Nationwide, practitioners have faced medical-board discipline, license revocation or even criminal prosecution for allegedly inappropriate prescriptions to patients suspected of using opiates for abuse, sale or suicide—in some cases despite evidence that the charges are baseless. These risks for doctors pose an additional barrier to their willingness to provide pain relief for PWAs, even though a 1998 study found that physicians are rarely investigated for prescribing opiates as pain medications.

Meanwhile, people in recovery often must battle their own fears about relapse and the disapproval of their peers in 12-step programs (see "Feelin' No Pain"). A "delicate balance often exists between pain control and relapse," Newshan says. But, she adds, patients can work closely with health care providers to maintain that balance, jointly setting limits and goals for narcotic therapy and communicating frequently about the patients' feelings.

Another concern of many doctors and patients is that side effects of opiates, such as drowsiness, constipation, nausea and confusion, may prove overwhelming. But these problems can generally be anticipated and managed, according to several studies. Drowsiness and confusion sometimes disappear within a week of beginning a drug regimen. If they don't, a reduction in dosage often alleviates the symptoms. Mild stimulants such as caffeine can also reduce sedation and improve pain relief. If they don't work, stronger stimulants such as Ritalin and Dexedrine can be used (although both can be addictive). Dietary changes such as increasing fiber intake or using supplemental magnesium can lessen or eliminate constipation, while several medications can reduce nausea.

Besides fears about medications, a key factor in the undertreatment of HIV-related pain is lack of communication: Doctors and nurses sometimes don't give patients much opportunity to report pain and may discount the seriousness of the problem when PWAs do speak up. And some patients have trouble expressing their concerns. Wendye Robbins, MD, director of the pain fellowship at the University of California/San Francisco (UCSF), believes the communication blockages have deep roots. "I think clinicians often underestimate pain because our culture is phobic about suffering," she says. "Doctors are not trained to appreciate pain and suffering, and people are encouraged to be stoic. Patients don't want to tell the truth and doctors don't want to hear it. It makes them uncomfortable."

Pat Sawyer, a PWA from Venice, California, spent three days in severe pain when Crixivan caused kidney blockage. "It was excruciating," she says. "I couldn't sleep, I couldn't talk, I couldn't do anything except lie there writhing." While Sawyer was hospitalized and undergoing diagnostic tests, doctors and nurses repeatedly asked whether she was in pain. She told them that she was, yet no one offered her any pain meds. Only when the anesthesiologist came just before the insertion of a kidney shunt did she learn that the hospital's policy was to dispense opiates only when a patient specifically requested them. Even then, when she asked for painkillers, "the nurse said she'd bring me Tylenol," Sawyer says. "I said, 'Tylenol? I need something stronger.'" The nurse said she would have to check with the doctor. An hour later, Sawyer finally received Demerol (meperidine, an opiate analgesic similar in effect to morphine), which allowed her to

sleep for the first time in days. All the while, Sawyer had assumed that doctors hadn't prescribed pain medications because they would interfere with her kidney function. So for days she lay in misery when her pain could have ended in minutes.

Sawyer's problems arose from misunderstandings on both sides. She didn't realize that she had the right to receive pain relief, and the doctors and nurses failed to obtain enough information to accurately assess Sawyer's pain. Because there is no "test" for pain, health care providers have to listen to and evaluate patient reports of it. "A big problem is that pain is totally subjective," Newshan says. "You have to go by what patients say. A lot of providers are not comfortable going by patient reports. They're used to looking at test results."

To make matters worse, most patients barely have time to air their concerns with their physicians. "One study reported that patients had 28 seconds to tell the doctor their complaints before the doctor took over the visit," Breitbart says. PWAs "put things like pain, fatigue and other quality-of-life issues on the back burner because they want to make sure more urgent issues are addressed," he adds. Fear of being labeled a "problem patient" can also influence PWAs to underreport pain. "They don't want to be seen as complainers," Newshan says.

Fortunately, efforts have been growing in recent years to educate physicians about the importance of pain management, both in medical schools and in continuing education programs. Among oncologists, such programs have greatly improved rates of pain treatment for cancer patients over the past decade. But solving the problem of inadequate pain treatment in PWAs will require involvement of providers and patients alike, suggests William Holzemer, chair of the department of community health systems at the UCSF School of Nursing. "A lot of it is education. I'm a firm believer that the way to change this is by changing patients' expectations," Holzemer says. "We need to do provider teaching, but we also need to do patient or client teaching. Patients need to know what to expect, what they don't have to tolerate and how they can speak up for the relief they deserve."

NO COMPLAIN, NO GAIN

When talking to doctors or nurses about pain, remember these seven tips:
1. Be sure to note all the places where you feel pain.
2. Describe the pain as well as possible. Is it burning? Shooting? Sharp? Is it different at different times?
3. Describe the pattern of the pain. Does it occur at predictable times? When does it feel better or worse?
4. Describe severity. How bad is the pain on a scale of one to 10?
5. Report the amount of relief gained through medication or nondrug strategies.
6. Detail how the pain impairs your routine functioning. Are you able to work? Move? Enjoy things?
7. Don't hesitate to demand relief, and don't be satisfied until you get it.

HOW TO SPELL R-E-L-I-E-F

Pain Treatment Ladder

The chart below features World Health Organization's "analgesic ladder" for managing cancer pain—also accepted for HIV-related pain. These medications are to be used in a stepwise fashion, escalating as pain worsens or medication becomes ineffective.

FOR MILD PAIN	
Acetaminophen (Tylenol)	Can deplete levels of glutathione, a vital nutrient for liver and immune function
NSAIDs (Nonsteroidal anti-inflammatory drugs)	
Aspirin (Bayer) Ibuprofen (Advil) Naproxen (Aleve)	Long-term use can cause gastrointestinal bleeding
FOR MILD TO MODERATE PAIN	
Weak opiates*	
Codeine Hydrocodone (Locet, Lortab, Vicodin)	Often combined with NSAIDs or acetaminophen
FOR MODERATE TO SEVERE PAIN	
Strong opiates*	
Morphine (Roxanal, MS Contin, Oramorph SR)	Available in oral and sustained-release forms
Levophanol (Levo-Dromoran)	
Oxycodone (Percocet, Percodan, Roxicodone)	Considered weak opiate when used in lower doses combines with NSAIDs
Hydromorphone (Dilaudid)	Available in suppository or injectable form; acts quickly
Methadone (Dolophine)	Oral forms have good potency
Meripidine (Demerol)	Toxic metabolite can accumulate, especially in people with impaired kidneys
Fentanyl	Available in transdermal patch form; acts gradually, long-lasting

*Side effects can include nausea, vomiting, constipation, drowsiness, confusion and breathing difficulties. Physical dependence can develop.

Treatments to Enhance Painkillers

Treatments listed below can be added to enhance other medications (or used alone).

TRICYCLIC ANTIDEPRESSANTS
Nortriptyline (Pamelor)
Amitriptyline (Elavil)
Desipramine (Norpramine)
SSRI ANTIDEPRESSANTS
Afluoxetine (Prozac)
Paroxatine (Paxil)
Sertraline (Zoloft)
STIMULANTS
Caffeine
Dextroamphetamine (Dexedrine)
Methylphenidate (Ritalin)
ANTIHISTAMINES
Hydroxyzine (Vistaril)
ANTI-ANXIETY DRUGS
Alprazolam (Xanax)
Clonazepam (Klonopin)
STEROIDS
Dexamethasone (Decadron)
ALTERNATIVE THERAPIES
Acupuncture
Distraction
Guided imagery
Relaxation techniques
Positioning techniques
Massage
Biofeedback

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