Initiatives in End-of-Life Care

Focus: Pain Management

Advances in State Pain Policy and Medical Practice

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States highlighted in red have medical board policies relating to the use of controlled substances for pain management (see p. 6).


A patient with pancreatic cancer uses the treadmill while controlling his pain with maximum doses of Percocet (oxycodone/acetaminophen). This patient died four months later while on hospice care in California.
A Rhode Island woman who has had breast cancer for the past 12 years experienced a painful recurrence. Just a few months into treating the recurrence, her physician, Joan Teno, M.D., initiated a regular morphine treatment regimen for her pain, a move Teno says families and her colleagues often resist. But for two-and-a-half years, morphine “has provided this patient with a high quality of life,” Teno says. Teno, a practitioner and researcher, believes her patient would not be living so long and productively if she were in daily pain.

Like many pain experts, Teno believes early, aggressive pain treatment lengthens life—the opposite of what so many patients, families, and medical practitioners assume. “Being in severe pain takes over everything. You do nothing but focus on that pain,” Teno says. “With opioids, things become tolerable.”

“Opioids” are pain medications, like morphine, derived from opium, or synthesized to behave like opium derivatives. Opioids are commonly known as narcotics, a law-enforcement term whose connotations make many pain-policy reform advocates, including Teno, bristle, because opioids prescribed appropriately and knowledgeably don’t have the implied effects of stupor and addiction.

Like most opioids, morphine has no dosage ceiling, and some patients need 1,000 mg or more every hour to reduce the pain to a level at which they can function, says Joanne Lynn, M.D., director of the Center to Improve Care of the Dying. But many physicians fear they’ll lose their licenses by prescribing opioids in such staggeringly high doses and, as in the case of Teno’s patient, for more than a brief time.

Because of cultural misperceptions and ignorance about opioids, patients and their families are often reluctant to accept them and physicians are reluctant to prescribe them early and aggressively. The result is widespread undertreatment of pain. Studies and policy statements confirm the undertreatment of many kinds of pain in a variety of settings. In its 1994 guidelines on cancer pain management, the Agency for Health Care Policy and Research (AHCPR) stated that 90 percent of cancer pain could be controlled “through relatively simple means”—with existing, and legal, medications. In 1995, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) found that among patients with life-threatening illness who were conscious, half of them said, by their families’ report, that they spent most of their last few days in moderate to severe pain.

But undertreatment of pain persists as “a strikingly large problem,” Teno says. A study published last year in the Journal of the American Medical Association found that 39 percent of elderly cancer patients in nursing homes experienced daily pain, but only 12 percent received treatment. The study did not rate the patients’ level or kind of pain, “but we do know that these were patients with cancer and with daily pain,” Teno says. “A person with cancer pain should receive treatment. I find this outrageous, shocking, and scandalous.”

Myths and Fears About Opioids
Though most pain-treatment experts agree that existing medications, including opioids, can control most kinds of pain, the public continues to equate them with addiction and death. “I get a lot of family members who say, ‘I trust your services, I read the literature you’ve given us, and on an intellectual...”

“Addiction among patients who use opioids for pain management is exceedingly rare.”
David Joranson, M.S.S.W., Pain and Policy Studies Group
level I’m willing to believe you, but on a visceral level I just can’t believe that you can take these medications and not get addicted,” says Richard Payne, M.D., chair of Pain and Palliative Care Services at Memorial-Sloan Kettering Cancer Center.

A common misperception is that patients are addicted when they become physically dependent upon opioids to control pain. Pain-management experts are eager to correct this confusion. Addiction—or psychological dependence—is a behavioral disorder characterized by compulsive seeking of mood-altering drugs and continued use despite harm. Physical dependence is a normal response of the body to a substance characterized by signs of withdrawal if drug use is stopped.

“Physical dependence is an expected result of opioid therapy. Addiction among patients who use opioids for pain management is exceedingly rare,” says David Joranson, M.S.S.W., senior scientist and director of the Pain and Policy Studies Group (PPSG) at the University of Wisconsin–Madison. “It’s so important to be clear about these terms,” Joranson says.

State Cancer Pain Initiatives
“Pain management is a relatively young field,” says Joranson, who came to the PPSG from the Wisconsin Cancer Pain Initiative (WCPI) and the state’s controlled substances board (CSB). Pain management emerged as a separate science in the mid-1980s, along with the development of state initiatives to improve cancer pain treatment. Wisconsin’s initiative was developed in response to the 1986 congressional debate over the Compassionate Pain Relief Act, which would have given heroin limited legal use. The CSB opposed heroin legalization because legal pain medications like morphine were just as effective for pain treatment as heroin, but underused by physicians. After helping to defeat the heroin bill, the CSB started the WCPI, which made cancer patients’ access to existing, legal pain medications one of its missions. Now every state has a cancer pain initiative.

“Triplicate” Laws and the War on Drugs
“The whole discussion about addiction in this country has made people with pain the victims of the ‘war on drugs,’” says Kathleen Foley, M.D., a neurooncologist at Memorial-Sloan Kettering Cancer Center and director of the Project on Death in America. Regulatory focus on diversion of prescription drugs to illicit uses has hampered pain management by prompting some states to enact restrictive prescription monitoring laws and regulations. These vary from state to state, but one approach requires physicians to use a special state-issued form when prescribing controlled substance—an approach commonly known as a “triplicate” law because most multiple-copy forms are in triplicate. Of the 17 states that have prescription-monitoring programs, seven still require special forms (the others have converted to electronic monitoring). Programs in these seven states monitor prescriptions for more than one-third of the U.S. population.

Payne, who is licensed to practice medicine in New York, Ohio, and Texas, cites “triplicate laws” as the number-one barrier to better pain management. The method is invasive: “There’s the sense that you’re being watched,” Payne says. Joranson notes that many physicians in “triplicate” states avoid the hassle by not even requesting the forms.

The result for patients is reduced access to pain treatment. But the data are clear (as the charts above illustrate) that for many years the abuse of morphine—the standard treatment for cancer pain—has remained essentially unchanged.

Increasing awareness of the need for better pain treatment recently has spurred dialogue between the medical community and the regulatory and law-enforcement communities. State-level policy makers are participating in this dialogue and working to improve pain treatment by

- removing legislative barriers to pain treatment
- relieving physicians’ fears of being sanctioned for appropriate prescribing, and
- creating a policy environment for better pain treatment.
Removing Legislative Barriers to Pain Treatment

Out of fear of abuse and diversion, and to hold the lid on exploding medical costs, states have built legal hoops that have physicians and patients scrambling. For example, some state laws

- limit patients’ ability to get a prescription for opioids filled if it is written by a physician practicing in another state
- put absolute per-month, dollar-amount restrictions on prescription-drug reimbursement.

If you were, for example, a cancer patient living in a state where the above laws apply, you could run into the following trouble:

- You have found a cancer specialist in another state, and that physician is treating your cancer, including the pain it causes, giving you hope of returning to work, regaining your life—but you can’t get your prescriptions filled in your hometown.
- You are a patient with advanced cancer. To control your pain, you need 400 mg of morphine per day—a standard dose for chronic cancer pain treatment. But your prescription plan has a limit of $1,000 per year. You must pay the rest out of pocket. (By contrast, your outpatient intravenous chemotherapy is fully reimbursed.)

“Morphine is among our cheapest drugs,” says Joanne Lynn, but 400 mg per day might cost roughly $7,500 per year. With a prescription plan reimbursing only $1,000 of that, the patient is left to pay $6,500, a high out-of-pocket amount for many individuals to cover. Those who are poor or uninsured might be able to afford even less.

Many states are revising their laws to eliminate undue restrictions on pain management while continuing to protect public health.

States Convert to Electronic Prescription Monitoring

Some of the most populous states—California, New York, Illinois, and Texas—are converting from triplicate forms to “electronic data transfer” (EDT) monitoring, whereby pharmacies use telephone lines to transfer prescription information to monitoring agencies, making the monitoring system less invasive, advocates say.

Those working in California for pain policy reform hope the conversion will be finished within a year. Betty Ferrell, Ph.D., FAAN, chair of the Southern California Cancer Pain Initiative, is optimistic: “The Initiative is in contact with all the parties involved in making that happen.”

New York’s recent conversion to EDT still requires physicians to use a special prescription form. Another revision New York has passed, and other states are considering, amends controlled-substances laws to state that one of their primary intents is to foster legitimate medical opioid use.

“States can include language in their controlled-substances laws that recognizes the treatment of pain as a public-health issue and frames their policies to provide appropriate treatment for chronic pain.”

Kathleen Foley, M.D., Director, Project on Death in America

Kathleen Foley thinks this is one of the most important contributions states can make toward fostering more balanced attitudes about pain treatment. “States can include language in their controlled-substances laws that recognizes the treatment of pain as a public-health issue and frames their policies to provide appropriate treatment for chronic pain,” Foley says.

The Role of Pain-Treatment Legislation

Twenty-five states have adopted pain-treatment legislation. Often called “intractable pain treatment acts” (IPTAs), these laws are designed to reduce physicians’ fear of sanctions by providing immunity from discipline, though not from investigation, for physicians who prescribe opioids for “intractable” pain.
The PPSoG, however, points out that IPTAs put undue restrictions on medical decision-making and patient access to pain medicine by
- defining medical use of opioids as a “therapy of last resort”
- implying that opioids can be used for pain only in cases where the cause of pain cannot be removed
- requiring evaluation of the patient by a second physician
- excluding pain patients with a history of drug abuse (Joranson, 1997).

Once enacted, such restrictions are difficult to rescind or adapt to advances in pain-management science.

IPTAs also carry a semantic conundrum. “Labeling pain ‘intractable,’” Joranson says, “implies that medicine can do nothing to alleviate the pain. But in fact chronic pain is generally treatable. Existing treatments, including medications, can relieve most if not all pain.”

The Role of Task Forces, Pain Commissions, and Coalitions

New York’s legislative reform was spurred by a series of recommendations made last year by the state Ad Hoc Committee on Pain Management, commissioned in 1997 by the Department of Health. The committee’s January 1998 report is an example of comprehensive reform that crosses state-level policymaking boundaries, with input from the medical, nursing, hospital, nursing home, home care, hospice, law enforcement, and legal communities (DeBuono, 1998). “State pain commissions can do a wonderful job of uniting all these parties,” says June Dahl, Ph.D., director of the Wisconsin Cancer Pain Initiative.

The New York Department of Health also has initiated a coalition, funded by The Robert Wood Johnson Foundation’s Community-State Partnerships to Improve End-of-Life Care Program (C-SP). It will hold grassroots pain-management education sessions at churches, schools and other community-based locations. Thirteen of 17 state coalitions funded thus far by C-SP have identified pain-management as a major problem in end-of-life care.

Other initiatives around the country tackling pain policy as part of end-of-life-care reform are being funded in part with public support. In addition, some cancer pain initiatives are expanding their concern to other types of pain, in effect becoming general pain initiatives.

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For the complete New York Ad Hoc Committee on Pain Management report and New York’s new controlled substances law, see the Department of Health website: www.health.state.ny.us/nysdoh

For the American Pain Society’s Quality Improvement Guidelines for the Treatment of Acute Pain and Cancer Pain, visit the APS website: www.ampainsoc.org/pub

The Mayday Pain Resource Center (MPRC) is a central source that collects a variety of materials including pain assessment tools, research instruments, materials on patient education and quality assurance, and other resources. MPRC publications are available through their website: www.mayday.coh.org
Bringing Better Pain Management into “Ordinary Medical Practice”

Fear of regulatory scrutiny continues to be the most common reason physicians give for not providing adequate treatment for chronic pain (Martino 332). Potent and persistent, this fear is handed down from one generation of medical residents to the next. “Research shows that the way physicians really learn is not through books but through one-to-one contact. Generations of care givers have been trained to stigmatize opioids,” says Sandra Johnson, J.D., L.L.M., provost of St. Louis University and a specialist in medical ethics and end-of-life care issues. Physicians’ fear of regulatory reprisal logically calls for better communication between physicians and regulators.

To this end, the Oregon Board of Medical Examiners holds workshops with physicians to clarify its stand on prescribing practices and to urge physicians to use the board’s standards in their practices. Sometimes these workshops actually boil down to one-to-one contact: “Last weekend I went down to southern Oregon and gave a talk that drew literally a couple of people,” says Board Director Kathleen Haley, J.D. “A couple of people is OK in my book because one was a chief of staff, and he oversees hundreds of physicians, and those physicians see hundreds and hundreds of patients.”

Joranson, who has educated members of every state medical board about the false assumptions commonly held about opioids, believes that the risk of regulatory scrutiny is declining, and that it is now more a perceived than real threat for most physicians. Physicians treating terminal cancer pain are rarely investigated. But investigation is time-consuming and subjects the target physician to social suspicion that can hurt a carefully built practice.

Easing Physicians’ Fear Through Pain-Treatment Guidelines

Some medical boards are attempting to ease physicians’ fear of investigation by adopting pain-management guidelines. Those working to ease tensions between regulators and clinicians believe pain-treatment policy must integrate pain management into “ordinary medical practice,” as Joranson puts it—rather than treating it as a separate medical practice with its own (usually tighter) restrictions, as IPTAs do. Because state medical boards—not legislatures—are charged with ensuring citizens receive competent medical care, many working in pain policy reform say pain-treatment guidelines are a key to reducing physicians’ fear of sanctions. The Federation of State Medical Boards’ model guidelines on the use of opioids in pain management, released in May 1998, are often cited as an example of progressive pain policy because they

- accept opioids’ medical legitimacy
- reject quantity and chronicity of prescribing as regulatory measurements of good medical practice
- state that the board will not discipline a physician for failing to adhere strictly to the guidelines if good cause is shown for deviation.

Many pain policy reformers favor the model guidelines over IPTAs because the model guidelines

- do not carry IPTAs’ undue restrictions (see p. 5)
- are more flexible than laws and more relevant to clinical practice, thus better able to keep up with advances in pain management science.

Johnson, for one, has written articles extolling pain treatment acts’ benefits, but she, too, prefers progressive medical-board guidelines. The DEA has endorsed the FSMB model guidelines, and the Kansas medical board adopted them immediately.

But guidelines in general also have their drawbacks: they depend upon board willingness to enforce them, and they can change with changes in board attitude and membership.

Investigating Undertreatment, Not Just Overprescribing

Susan Tolle, M.D., a practicing internist who directs the Oregon Center for Ethics in Health Care, would like to see boards define quality indicators for pain undertreatment.

“At the moment, physicians in other states can get into trouble only by writing prescriptions. But refusing to write any also falls into the scope of bad practice,” Tolle says.

The Oregon medical board recently announced its intention to discipline a physician for failing to give six seriously ill or dying patients adequate pain medication. However, making investigation of undertreatment a policy may be premature until boards and physicians communicate more clearly about actual expectations regarding opioid use. In any case, some experts believe discipline should emphasize education, not punishment: “To take them to task for something they were never educated properly about in the first place is too harsh,” says June Dahl.

Oregon has also established palliative-care teams that model good pain-management practices “for everyone from residents up to established senior faculty,” Tolle says. “Someone needs to teach how to take the guidelines and make them come alive at the bedside.”
Strengthening Pain Assessment: A Role for Nurses

Just as nurses assess temperature, blood pressure, pulse rate, and respiration, assessing patients’ pain levels on a zero-to-10 scale, where zero indicates absence of pain, is the first step toward recording the strength and duration of a patient’s pain. Without such a record, accountability is impossible.

“People would never be allowed to lie around in a hospital bed with a fever of 105, but a lot of people lie around in the hospital with pain scores of 9 out of 10,” Dahl says. “Major emphasis has to be placed on assessment. You can’t treat what you don’t know about.”

Assessing pain as the “fifth vital sign” was the foremost action-item endorsed by 30 leaders of national nursing organizations at a symposium on “Peaceful Death” late last year. The American Academy of Nursing has committed to stimulating state licensing agencies to develop a fifth-vital-sign quality indicator for site-evaluations.

Nurses are likely leaders in implementing fifth-vital-sign programs at their institutions. Nurses are also looking toward the release of the Joint Commission on the Accreditation of Healthcare Organizations’ new pain treatment guidelines. The new guidelines will include hospitals, home care, ambulatory care and behavioral health facilities. They are now in review for release next year.

A Role for Pharmacists

The Mississippi Board of Pharmacy (BOP) is working with the state’s medical and nursing boards on a team approach to palliative care that can be replicated across the country. Hospice medical directors and pharmacists make rounds together, with the physician developing plans of care and the pharmacist permitted to implement the plan. Mississippi Medicaid is the first in the nation to pay pharmacists to work with physicians to assist in managing patient care plans. “In a hospice atmosphere, you don’t have the physician all the time. The most easily accessible medical professional is the pharmacist,” says Mississippi BOP Director William “Buck” Stevens. He hails this model as “a bridge to enable everybody to focus on patients.”

States can

• ensure patients’ access to early, aggressive pain management by providing timely referral to hospice

Creating a Positive Environment for Better Pain Management

There are many ways in which medical professionals and policy makers alike can help create a positive environment in which pain-management policy reform can more easily occur.

Medical professionals can

• persuade state licensing agencies, health departments, aging offices, and other officials to collaborate on pain management quality indicators
• urge state-supported medical schools and teaching hospitals to include better and more accurate pain management information in curricula and training

• encourage states to move away from declaring patients “terminal”—usually a requirement for hospice admission—and toward a definition of “life-limiting illness,” which would permit hospice admission earlier in treatment of a slow-moving terminal illness
• ensure patients’ access to early, aggressive pain management by providing timely referral to hospice

States can

• provide funding and support for their cancer pain initiatives, many of whose staff cite lack of funding as a major impediment to their work
• through licensing agencies, develop state pain-management standards for nursing homes
• with the influence of state attorneys general and agency directors, urge the federal Health Care Financing Administration (HCFA) to develop standards and provide adequate funding
• guarantee Medicaid funding of palliative care in a variety of settings
• create and fund media campaigns to educate citizens to expect and ask their physicians for better pain management
• include a pain management expert on the state medical board and in the office of professional conduct, to conduct a pre-review
• provide protection for pharmacies located in neighborhoods with high risk of robbery
• encourage professional and trade associations, including managed care organizations, to promote pain management.
Many reformers believe improving pain management ultimately depends upon the public’s willingness to demand it. The message that “pain can almost always be controlled” has reached Oregon citizens through strategic media-relations campaigns coordinated by reformers like Tolle. She regularly meets with reporters regarding progress on Oregon’s policy reform successes in end-of-life care—of which pain-management reform is a primary aspect. “The primary force for change is public education,” Tolle says. “Patients need to demand better pain treatment.”

To “get the issue on the public radar,” says Jim Guest, executive director of the American Pain Foundation, state agencies can

- fund print-media and advertising campaigns through the health department
- require health plans to distribute pain-management information and end-of-life care to all enrollees
- develop leaflets for doctor’s-office distribution about “How to describe your pain,” “How to talk to your doctor about pain,” and “Pain can usually be controlled”
- declare a Pain Awareness month, week, or day
- disseminate consumer information through chapters of nonprofit groups, public libraries, and local community groups.

“What’s missing for me is that consumers are not outraged and out there demanding better care,” Joan Teno says. “We need to educate them that you can have your pain managed to the level that you desire.”

Bibliography


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