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The Humanistic Dimensions of Pain and Suffering in the Clinical Setting
By Ben A. Rich

That pain and suffering are inherently personal and subjective experiences is an inescapable fact and a fundamental barrier to the effective assessment and management of pain in the clinical setting. As Scott Fishman, my colleague in Pain Medicine at the University of California–Davis observes: “Pain is an untestable hypothesis.”

The problematic nature of pain is exacerbated because language fails us when we seek to communicate the experience. As Virginia Woolf observed:

English, which can express the thoughts of Hamlet and the tragedy of Lear, has no words for the shiver or the headache... The merest schoolgirl, when she falls in love, has Shakespeare or Keats to speak her mind for her, but let a sufferer try to describe a pain to a doctor and language at once runs dry.

Moving from the literary perspective to the philosophical, Elaine Scarry conveys a similar insight:

Physical pain does not merely resist language, but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human makes before language is learned.

“That pain and suffering are inherently personal and subjective experiences is an inescapable fact and a fundamental barrier to the effective assessment and management of pain in the clinical setting.”

Perhaps such insights are the reason that pain assessment tools commonly used in the clinical setting prefer numbers and pictures to words.

Pain, Suffering, and the History of Medicine
In the history of medicine, concerns about the relief of pain and suffering have waxed and waned. Throughout much of the ancient and early modern eras, maxims such as “cure when possible but relieve suffering always” were axiomatic. Yet an often-quoted “prayer” attributed to the medieval physician-philosopher Moses Maimonides anticipates the paradigm shift that will occur, much later, with the advent of modern, high tech medicine: “Never forget that your patient is a fellow creature in pain, not a mere vessel of disease.”

As Maimonides feared, with the rise of the curative (in contradistinction to the palliative) model of medicine, pain became primarily a symptom of underlying disease. Solving “the riddle” of the patient’s disease, as Yale surgeon Sherwin Nuland has famously written, soon became

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Unmasking the Problem of Pain...Where Do We Go from Here?

From the cry and distress of birth to the undeniable effects of time and gravity on our aging bodies, pain is a common experience. It reminds us of our mortality, protects us from injury, and often calls us to heroic fortitude. But pain that is denied, disparaged, undertreated, or mismanaged does nothing good for the millions of Americans who suffer its ill effects on a daily basis.

This issue of Practical Bioethics looks at the nature of pain, its history in modern medicine, and its mysterious impact on the covenant relationship of patient and physician. More particularly, this publication raises the ethical issues that acute or chronic, malignant or nonmalignant pain creates for patients, their families, healthcare providers, and policymakers across the broad expanse of our responsibility for each other.

Our inconsistent and confusing response to pain creates far more than physical discomfort. The problem of pain points to untold and unnecessary suffering. Depression, isolation, and lost hope cast a dark shadow on those who hurt, and lost productivity costs families and employers millions of dollars. Yet our conceptual knowledge and pain treatment modalities far outstrip our will to end unnecessary pain and suffering. Are we still so short of reason and courage that we will allow myths—ancient stories about the transforming power of pain or modern stories about drug addiction—to rule our actions?

Aging gracefully and dying well is a right that each of us must claim for self and family; it is also a possibility that we are obligated to extend to others. Our hope in this issue of Practical Bioethics is for a collective commitment from patients, practitioners, and policymakers to put the problem of pain clearly at the core of this discussion.

John G. Carney

John G. Carney, contributing editor for this issue of Practical Bioethics, is the Center’s vice president for aging and end of life. For more information about our programming in this area, see www.practicalbioethics.org.

Humanistic Dimensions
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the mission of the foremost practitioners of the art and science of medicine, not “pursuit of the welfare of the individual patient.”

One tragic consequence of this shift in the prevailing model of medical practice is the epidemic of undertreated pain and unnecessary suffering in contemporary patient care. It is perhaps fitting that the most compelling indictment of modern medicine has been leveled by one of its most illustrious and articulate practitioners, Eric Cassell:

The test of a system of medicine should be its adequacy in the face of suffering...Modern medicine fails that test. In fact, the central assumptions on which 20th Century medicine is founded provide no basis for an understanding of suffering.

Diagnosing the Problem

Undertreated pain is a national public health problem of major proportions. Yet an exquisite irony pervades the explanations we offer for the epidemic. Its root causes: ignorance (exacerbated by myths and misinformation), indifference (the failure to make pain relief a priority in patient care), and fear (of regulatory scrutiny and potential liability) are the antithesis of our image of how medical practitioners should be motivated.

“Undertreated pain is a national public health problem of major proportions and a national tragedy. Yet an exquisite irony pervades the explanations we offer for the epidemic.”
We have known for decades that medical school, nursing, and pharmacy curricula are virtually devoid of formal courses on the assessment and management of pain. Moreover, when medical students leave the lecture halls for the wards and practice settings of internship and residency, they are mentored by senior faculty who are encumbered by ignorance, mythology, and misinformation. Many still believe that the extended use of opioids for pain management leads to addiction, and that the risks and side-effects of opioid analgesia (e.g., respiratory depression or sedation) outweigh the benefits.

The consistent failure of the medical profession to address these deficits in the education of physicians renders it vulnerable to the charge that it has actually cultivated its ignorance about the assessment and management of pain and the integral relationship between pain relief and acceptable patient care.

Pain and Public Policy

We have finally — in the last twelve to fifteen years — initiated a public policy response to the phenomenon of undertreated pain. The response implicitly recognizes that physicians must be part of the solution. Guidelines, regulations, policy statements, and statutes have been crafted at the state and national level to convey the message that prompt, effective, and continuous assessment and management of pain should be a priority in patient care.

Medical boards have been admonished of their responsibility to disavow regulatory practices that punish physicians for using opioid analgesics in a conscientious and responsible effort to manage pain. Such boards can also help dispel the widespread fears of physicians that prescribing such medications, except for patients at or near the end of life, will lead to heightened scrutiny, formal investigation, and potential disciplinary action.

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that symbolize competence. In most cases, however, it is impossible for a patient to accurately judge a physician’s competence or character. The gap between the physician’s medical expertise and our own knowledge — and our perception of the doctor’s status and power — makes it necessary for patients to rely on a social contract between medicine and society. We rely on the assurance of others that our physicians have essential virtues.

Grounding Professional Integrity

In exchange for the benefits that physicians give us individually and collectively as a society, we contribute significantly to their education. We allow medical students to experiment on us while they are in training. We compensate physicians at a high level. We give them a revered title, special social status and privileges, and exemption from certain laws.

When asked how the integrity of the physician is preserved, many respond that physicians are bound by the Hippocratic Oath or the code of the American Medical Association (AMA). Although most physicians do take some oath at their graduation from medical school, Americans are shocked when they learn that physicians are not bound by any particular code of medical ethics and that the majority of U.S. physicians do not belong to the AMA.

In reality, the keepers of our trust in medical practitioners are members of state medical boards. Since the early twentieth century, these boards have assumed responsibility for promoting public health and for protecting the public from improper medical practice and unscrupulous behavior. It is ironic, therefore, that state medical boards have contributed to the undertreatment of pain.

Barriers to Pain Management

Many factors contribute to the inadequate treatment of pain: lack of education and training about pain management, restrictive and outdated state laws and regulations, fears about addiction among both providers and patients, and inadequate reimbursement for the treatment of pain.

The most prominent barrier, however, is fear. Physicians fear they will be investigated by regulatory agencies for prescribing controlled substances, despite repeated assurances that “prescribing opioids for pain management is legitimate if done in the course of professional practice” (Joranson et al. 2002).

Since the early 1990s, the Federation of State Medical Boards (FSMB) has worked with its members to remedy this situation. The FSMB gathers data, provides educational programs for its members, develops policy guidelines, and collaborates with other organizations that affect medical practice.

In 1991, the FSMB collaborated with the Pain and Policy Studies Group at the University of Wisconsin to survey members of state medical boards to learn their beliefs about prescribing opioid analgesics. The survey asked if it was “lawful/generally acceptable medical practice” to prescribe opioid analgesics for more than several months to treat patients with

- Chronic cancer pain
- Chronic cancer pain and a history of drug abuse
• Chronic noncancer pain
• Chronic noncancer pain and a history of drug abuse

Fully 75 percent of respondents thought it acceptable to provide ongoing treatment with controlled substances for cancer patients, but only 12 percent thought prescribing opioids was appropriate for chronic noncancer pain.

If the patient had chronic noncancer pain and a history of drug abuse, only 1 percent thought prescribing opioid analgesics for that patient was acceptable. In response to these disturbing results, FSMB sponsored a series of educational programs for medical board members across the country. Nevertheless, physicians continued to fear state regulatory boards, and their fears were exacerbated by highly publicized cases that the Drug Enforcement Administration, attorneys general, and other law enforcement agents had brought against physicians.

In 1998, with support from the Robert Wood Johnson Foundation, FSMB adopted Model Guidelines for the Use of Controlled Substances for the Treatment of Pain. This guidelines document was widely distributed and endorsed by the American Academy of Pain Medicine, the Drug Enforcement Administration, the American Pain Society, and other health-care providers and regulatory agencies. It was soon reflected in the policies, rules, regulations, or statutes in more than two dozen states.

The full force of the guidelines was blunted, however, by sensationalistic media reports regarding the diversion and abuse of OxyContin, a relatively new opioid analgesic. FSMB surveys taken in 1997 and repeated in 2004 indicate that the knowledge and attitudes of state medical board members have changed. The data also indicate that many barriers remain.

Taking the Lead

Last year, evidence about the continuing undertreatment of chronic and acute pain motivated FSMB to go further, and its board of directors adopted a Model Policy for the Use of Controlled Substances in the Treatment of Pain. The new policy asserts that
• Pain management is integral to the practice of medicine.
• Opioid analgesics may be necessary for pain relief.
• Use of opioids for other than legitimate purposes is a threat to all.
• Physicians have a responsibility to minimize potential for abuse.

This document provides a much needed ethical framework for the social contract between medicine and society. It articulates principles that reinforce the trust that underlies the physician/patient covenant. When diagnosed with a serious or terminal illness, most people ask their physicians three questions:
• What is wrong with me?
• What can you do to help me?
• Will I have pain?

To be told the truth, to be assured of care, to have one’s pain managed: these are reasonable expectations, and with FSMB’s guidance and leadership, physicians will not let their patients suffer needlessly.

References


―Myra Christopher, president and chief executive officer of the Center for Practical Bioethics, is a frequent speaker on bioethical issues and an advisor to many national organizations. She chairs the Initiative on End-of-Life Care of the National Association of Attorneys General and serves on the advisory committee for the Federation of State Medical Boards.―
One of the most contentious issues in pain management is the extent to which the nation’s declared war on drugs has contributed to the epidemic of undertreated pain. There is no question that many physicians fear the Drug Enforcement Administration and its ability, under the federal Controlled Substances Act, to investigate and prosecute physicians for inappropriately prescribing drugs or, in extreme cases, drug diversion or trafficking. When the ignorance, myth, and misinformation surrounding opioid analgesia combine with worry about state and federal regulatory scrutiny, then fear, which has been aptly characterized as “opiophobia,” becomes rampant in the medical profession.

When we declare a war on drugs but not on pain, physicians become conscripts in the war; patients become noncombatant casualties, and a fundamental principle of medical ethics, the duty to relieve pain and suffering, sustains grave collateral damage.

“Where do we go from here?”

We seem to be at a place in the evolution of our thinking about pain management in which for every step forward, we take at least one, if not two steps back. How do we help physicians fulfill their responsibility to patients with pain, especially pain that is significantly chronic and of nonmalignant origin?

A few examples will suffice to indicate our hesitant progress.

1. In the 1990s, state medical licensing boards adopted policies and guidelines emphasizing the importance of pain relief to good patient care and assuring physicians that they were not at risk for prescribing analgesics consistent with current clinical practice guidelines.

2. During the same time, the Joint Commission for the Accreditation of Healthcare Organizations modified its Accreditation Manual to emphasize the responsibility of healthcare institutions to assure that patients consistently receive effective pain relief.

But in the next decade:

1. State and federal regulatory agencies charged that physicians were inappropriately prescribing a new time-release pain medication – OxyContin – and state and federal law enforcement agencies charged physicians with substantial criminal penalties when a few patients encountered either medical or legal difficulties while under their care for chronic pain.

Again, on the positive side:

1. Juries in two civil actions — one in North Carolina in 1991, another in California in 2001 — awarded substantial damages to the families of elderly men whose cancer pain was not well managed in the last weeks of their lives.
Innovations and New Pain Treatments 1900 to the Present

by Marcia Meldrum

From 1940 to 1962

World War II brings improvements in surgery and anesthetic and analgesic nerve blocks. Nerve block clinics are started in the United States and Great Britain. A few doctors initiate pain research projects and begin to challenge conventional thinking. Over-the-counter pain relievers begin to proliferate. The Committee on Drug Addiction is reconstituted and sponsors the testing of alternatives to morphine.

1943: William Livingston suggests “vicious circle” model in Pain Mechanisms

1946: Henry Beecher suggests the influence of the cognitive and emotional “reaction component” of pain in “Pain in Men Wounded in Battle”

1947: Multidisciplinary pain clinics founded by Livingston in Oregon and by John Bonica in Tacoma, Washington

1948: Bernard Brodie and Julius Axelrod isolate acetaminophen (later marketed as Tylenol [1955])

1953: John Bonica publishes Management of Pain, begins promotion of multidisciplinary approach

1958: Raymond Houde and Walter Modell publish guidelines for clinical evaluation of analgesics, based on work of Beecher and Houde

1959: Willem Noordenbos’s Pain describes pain in the context of an interactive neural network

1962: Ronald Melzack and Patrick Wall publish joint article on “sensory mechanisms”

From 1963 to 1975

The watershed years. Discoveries and new ideas in physiology, pharmacology, psychology, and palliative care bring pain researchers and clinicians together in professional collaboration and open up new possibilities for research and treatment.

1964: Cicely Saunders first suggests the concept of “total pain”

1965: Melzack and Wall propose the “gate control” model of pain modulation

1967: Cicely Saunders founds St. Christopher’s Hospice, flagship of modern hospice movement, in SE London

1968: Wilbert Fordyce, Roy Fowler, and Barbara DeLateur describe behavior modification therapy for pain

1968: Richard Sternbach writes about pain as a learned response of the nervous system

1971: David Mayer, Huda Akil, John Liebeskind, and David Reynolds report analgesia from electrical stimulation of brainstem

1971: Melzack and W.S. Torgerson introduce the McGill Pain Questionnaire for pain assessment

1972: Presidential trip to China stirs new interest in acupuncture and other complementary therapies

1973: Bonica organizes international meeting of 350 pain researchers at Issaquah, Washington; group founds International Association for the Study of Pain

1973: Candace Pert and Solomon Snyder isolate the opiate receptor in neural tissue

1975: Journal Pain launched under editor Patrick Wall

1975: John Hughes and Hans Kosterlitz report on the discovery of enkephalin, the first known endogenous opioid

1975: John Loeser and colleagues report on pain relief through transcutaneous stimulation (an application of the gate control theory)

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From 1976 to 2005

An era of excitement and frustration. Neurophysiological, pharmacokinetic, and molecular research clarify the mechanisms of pain sensation and demonstrate that pain is indeed related to learning. New pharmacological analgesics are developed, but none that are universally effective or without side effects. Multidisciplinary pain programs are organized; behavioral modification is further developed as cognitive-behavioral therapy, but again fails to help all patients. In the absence of a better analgesic, pain specialists campaign for more patient access to opioids, but meet political and cultural resistance.

1977: American Pain Society founded
1977: R. Lee and P.S.J. Spencer publish review article on the use of tricyclic antidepressants in pain relief, spurring further research
1978: Robert Twycross presents evidence that cancer patients on long-term opioid therapy do not inevitably develop tolerance or addiction
1982: WHO expert group on cancer pain relief convenes and develops “three-step ladder” for analgesia
1983: American Academy of Algology (later the American Academy of Pain Medicine) founded as a multidisciplinary group to accredit and advocate for physicians specializing in pain management
1986: WHO publishes Cancer Pain Relief
1988: Gary Bennett and Y.-K. Xie develop chronic constriction injury rat model, which mirrors chronic regional pain syndrome in humans
1988: Richard S. and Kathryn A. Weiner found the American Academy of Pain Management to accredit and represent pain practitioners from non-medical disciplines
1991: C.J. Woolf and S.W. Thompson demonstrate induction and maintenance of central sensitization through NMDA receptor activation, a mechanism that perpetuates severe pain even after original triggering event ends
1994: K. Seibert and colleagues report on the role of cyclo-oxygenase 2 in inflammation and pain
1995: SUPPORT Study reports that 50 percent of patients in the study who were conscious when they died, were in moderate to severe pain at least half the time, according to their families
1997: James N. Campbell, Kathleen Foley and John Liebeskind establish the American Pain Foundation, the first grassroots organization to represent people in pain
1998: U.S. Federation of State Medical Boards (FSMB) adopts Model Guidelines for the Use of Controlled Substances for Pain
2000: M. A. Ruda and colleagues demonstrate that neonatal inflammation can lead to changes in neural processing – that pain during early development may affect an individual throughout life
2001: U.S. Congress declares 2001 to 2010 the Decade of Pain Control and Research
2001: Drug Enforcement Administration and twenty-one leading healthcare organizations publish a joint statement on achieving balance between good pain management and control of drug abuse
2001: Reports of OxyContin abuse appear in the press and trigger new actions against physicians who prescribe opioids for chronic pain
2004: DEA publishes jointly authored “Frequently Asked Questions and Answers” regarding opioid use for pain treatment on its website, then abruptly withdraws them
2004: FDA removes Vioxx, a cox-2 inhibitor analgesic, from the market after it is linked to increased risks of stroke and heart attack; Bextra, also a cox-2 inhibitor, will be removed the following year

2000: Joint Commission on Accreditation of Healthcare Organizations develops new mandatory standards for pain assessment and management
The message was clear: a standard of care for pain management can be established as law, and the failure of a physician to meet that standard will give rise to a finding of malpractice or elder abuse (as in the California case) and awards of compensatory and/or punitive damages (as in the North Carolina case).

But the response of physicians generally to these cases has been to conclude that they are between a rock and a hard place — at risk of regulatory sanctions if they aggressively prescribe opioid analgesics and vulnerable to liability claims by patients or families if they do not.

This one step forward, two steps back approach leads many to conclude that there is no safe middle ground in which to use opioid analgesia in pain management. A concerted and redoubled effort by policymakers, physicians, and the public is needed to eliminate this troublesome conclusion.

I would go further: If it is true that the duty to relieve pain and suffering goes to the very roots of physicians’ responsibility to patients, then modern medicine has become alienated from its roots. The existence of a causal relationship between regulating scrutiny of providers and the phenomenon of undertreated pain is compelling evidence of the medical profession’s loss of stature and political clout. It says, in effect, that physicians collectively can be bullied and intimidated by regulators and law enforcement into providing what they know, or should know, to be substandard patient care.

Regrettably, the regulatory environment that has contributed to rampant opiophobia in medicine and society, and which public policy initiatives have yet to adequately constrain, requires physicians to engage in acts of moral courage to ensure that their patients will not be subjected to unnecessary pain and suffering.

The time is ripe for medicine to return to its roots and core values, for, as a group of distinguished physicians wrote years ago in the New England Journal of Medicine (1989), “to allow a patient to experience unbearable pain or suffering is unethical medical practice.”

References


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Humanistic Dimensions

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The time is ripe for medicine to return to its roots and core values, for, as a group of distinguished physicians wrote years ago in the New England Journal of Medicine (1989), “to allow a patient to experience unbearable pain or suffering is unethical medical practice.”

Marcia L. Meldrum, PhD, codirector of the John C. Liebeskind History of Pain Collection at the University of California, Los Angeles, lectures and writes frequently on the history of pain and evidence-based medicine. She and her colleagues have undertaken oral history research projects on the history of pain science, pediatric pain management, and the history of human genetics.
African American male patient, age forty-two, was admitted to a skilled nursing unit after surgery for head and neck cancer with lymph involvement, newly diagnosed. Extensive excision of the tumor had been done, and the patient had a newly placed tracheostomy and feeding tube. His history included years of “living on the street” and active drug abuse at the time of admission. The patient was very anxious on assessment, focused on his tracheostomy, pulling on the connections, to “make sure they are working” and complaining of pain “eight-to-ten” on a scale of one-to-ten, with intensity focused in the area of his surgical wounds.

Although he receives morphine on an “as needed basis” he waits as long as he can to “ring the nurse” because he worries that asking for pain medication will “label him” with the staff. He also complains about not getting much sleep, and thinking often of the poor choices that got him “into this trouble.” He has anxiety related to “breathing through this tube, like I am not getting enough air in,” and ongoing pain, which “gets less but never gone.” He readily admits to “risky behavior,” which had alienated him from family and social support for some time and is willing to discuss his years of drug and alcohol abuse.

When the nurses and the attending physician describe the patient’s condition they explain that his anxiety is “probably related to being a druggie” and that his pain is mostly “drug seeking” in nature, as evidenced by his “calling for more medication a few times a shift,” and that he seems to “watch the clock.” They also note that this patient is a “homeless street person” who waited too long to seek help: he hasn’t held a job for some time, has no visitors, and is probably using his illness to feed his addiction.

1. How does this man’s history as recorded in the chart affect every encounter he has with healthcare professionals? What is presupposed by his “life on the streets”? by his active drug use in the past?

2. How is even his hesitation to ring the bell for more morphine interpreted on the basis of his past? What other behaviors do the nurses cite as evidence for this judgment? How does the patient explain his behavior? Is any consideration given to the possibility that what is past is past?

3. If a nurse were to walk into this patient’s room without any knowledge of his past, how would his waiting to receive further medicine be interpreted? His not having any company? His anxiety about his condition?

4. Review the articles and the time line in this issue. How would knowing something about the history of pain management change the way we treat this patient?

5. Suppose that this case were brought to you for an ethics consultation. Are concerns about the patient’s pain relief being “drug seeking” morally relevant?

6. Are any of the following circumstances morally germane: the patient’s homelessness, his joblessness, his apparently deliberate non-rehabilitation, his absence of visitors?

7. What biases do members of the clinical staff bring to this case? Are the biases justified? How do such biases affect the goals of care and proper pain management for this patient?

8. As a clinician, patient advocate, or member of the ethics committee, what policies or procedures do you recommend to insure that this patient and others will not receive unequal treatment because of these biases?
Mrs. W is a sixty-year-old African American woman with a recent diagnosis of breast cancer with metastases to the bone and lung. She has been married thirty-two years and has three adult children. Over the last month, she has experienced increasing pain that has not been effectively controlled by her physician. She has now been referred to hospice, primarily to get her pain under control.

After assessing the patient, the hospice nurse recommends long-acting Morphine 30 mg twice a day with short-acting Morphine for breakthrough pain every three or four hours as needed. Mrs. W is also placed on Dexamethasone for bone pain. After recommending this treatment, the nurse follows up with Mrs. W in twenty-four hours and finds that Mrs. W is still experiencing pain.

In discussion with Mrs. W and her husband, the nurse discovers that Mr. W allows his wife to take her long-acting Morphine but limits any additional pain medicine because he “doesn’t want her to become addicted.” He tells the nurse that her church is praying that she will be relieved of pain. Mrs. W complies with her husband’s wishes, but often grimaces when she is visited by hospice staff (nurse, clinical nursing aid, social worker, chaplain).

As Mrs. W continues to decline she and her husband finally agree to transfer her to an inpatient unit. Mrs. W dies four days after transfer to the inpatient unit, at peace and completely pain free.

Questions for Reflection and Discussion

1. Discuss the patient’s autonomy regarding her right to good pain control versus her decision to comply with her husband’s opinions regarding her pain medication. Is she acting autonomously? Does her ongoing pain detract from her competency and free choice? How can we determine Mrs. W’s state of mind?

2. What are the psychosocial, spiritual, and cultural issues that influence the pain management of this patient? How would you approach the integration of Mr. and Mrs. W’s belief in prayer and their right to participate in healthcare decision making?

3. Discuss the role of healthcare workers in respecting Mrs. W’s wishes while still wanting to provide her with effective treatment. Did they sufficiently inform the couple about the merits of morphine for pain control? Did they listen intently and respond to the couple’s concerns about addiction?
Barriers to Pain Management

- insufficient knowledge regarding the assessment and treatment of pain
- unsound beliefs and unsubstantiated fears of addiction, tolerance, dependence
- economic issues
- failure to identify pain as a priority in patient care
- fear of regulatory censure

If medicine is a moral enterprise, then we have ethical and medical reasons to challenge these barriers.

For more information on pain management and a glossary of pain terms, visit www.practicalbioethics.org.