Pain is humankind’s oldest problem. St. Augustine called it the “greatest evil” because he understood the unique ability of pain to interfere with all aspects of living, including the ability to attend to one’s relationship to God (Soliloquies 1.21).

In modern times, we have come to recognize the profound effects of unrelieved pain on the individual, the family, and society at large. Both physical and psychological aspects of a patient’s life may be affected, including the ability to work or perform activities of daily living, sleep patterns, emotional state (depression, anxiety, anger), and self-esteem. Social, familial, marital, and sexual relations may be impaired, and patients may become socially isolated as they are no longer able to participate in their usual activities.

On a societal level, the disability and lost workdays associated with chronic pain impose significant direct as well as indirect healthcare costs. Pain is the cause of 25 percent of all sick days taken yearly (U.S. News and World Report 1997). In fact, a recent survey noted that nearly 20 percent of Americans had either moved from their homes, changed jobs, or suffered significant change in their ability to work or live their lives as a result of chronic pain.

Even terminally ill patients commonly experience substantial pain (Pain in America 2003). Weiss et al. (2001) surveyed nearly one thousand terminally ill patients and observed that approximately 50 percent

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When my two brothers and I were kids, we had “torture contests.” Even as children, the ability to endure pain was, for some unknown reason, very important to us.

Some of the “special” challenges in our contests included physical pain, such as twisting one another’s arms, putting rubber bands on fingers for extended periods of time, and immersing our hands in ice water until we could no longer bear it. Other challenges were more existential in nature – that is, they were related to suffering.

For example, as “the girl” I was especially challenged when, after heavy rains, we would collect earthworms from the gutters, put them in a wash tub, then challenge one another to stand barefoot in the water. Or, knowing that I was terribly afraid of snakes, my brothers would often challenge me to hold rattlers dismembered from the most deadly of snakes and rub them against my arms and face. (I am so phobic about snakes that to this day I wouldn’t dream of trying on a pair of snake-skin shoes or carrying a snakeskin purse – no matter how fashionable.)

In the late 1970s, while caring for my mother who later died from stomach cancer, I became interested in pain from a different perspective, and until fairly recently, my personal and professional interest in pain centered primarily on the pain and suffering associated with terminal illness. However, in the late 1990s, while directing the Robert Wood Johnson Foundation’s national program, Community-State Partnerships to Improve End-of-Life Care, I became interested in pain and pain policy from a still broader perspective.

This development was initially fostered by David Joransen, director of the Pain and Policy Studies Group at the University of Wisconsin, Madison, and a member of our National Advisory Group. Joransen had originally declined to serve as an advisor because he feared that our work would unintentionally have a negative consequence on those suffering from chronic pain. When I promised to do all that I could to ensure against this outcome, David agreed to serve, and he was a wonderful advisor. We are grateful to him for his service to the Community-State Partnerships and for educating us about the undertreatment of pain among those who are chronically ill.

With David as a mentor, I have been involved in chronic pain work for about ten years. And, since beginning this work, I have also learned about pain from people like June Dahl, Betty Ferrell, Richard Payne, and others who have written for this issue of *Practical Bioethics*. They are wonderful teachers, and I am very grateful to them.

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Pain management is at the core of the covenant between physicians and patients. In recent years, however, that covenant has been thrown out of balance by a number of factors, including a lack of education in the medical community and a federal government campaign to prevent abuse of controlled substances.

The national media have contributed to this imbalance by playing up a very small number of cases in which physicians have been prosecuted and sentenced — in some cases, unjustly — for criminal offenses connected with prescribing controlled-substance painkillers to patients with chronic pain. Consequently, many physicians, especially those who are not pain management specialists, are now reluctant to prescribe pain medications, particularly opioid-based painkillers. As a consequence, patients continue to suffer from chronic pain despite the availability of proven and safe therapies for treatment.

Since 2006, the Center for Practical Bioethics has addressed this imbalance head-on through its Balanced Pain Policy Initiative. This initiative, a three-way partnership comprised of the Center, the National Association of Attorneys General (NAAG), and the Federation of State Medical Boards (FSMB), is seeking factual, research-based answers to key questions. With the answers in hand, the Center will publish its findings and convene meetings on national and regional levels to review the data and use them to help identify effective ways to restore balance to pain-treatment policy within the medical and law enforcement communities.

The Balanced Pain Policy Initiative, which has currently researched over 1,000 criminal and state medical board cases involving 725 physicians, is seeking answers to the following questions:

1. What kinds of physicians have been prosecuted or administratively reviewed for offenses involving the prescribing of controlled-substance pain medications? Are disproportionate numbers of them pain medicine specialists? Are disproportionate numbers of them elderly, ethnic minority, or graduates of foreign medical schools?

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Many physicians are reluctant to prescribe pain medications, particularly opioid-based painkillers.

2. Are physicians in some states more likely to be involved in such cases than those in other states? Do disproportionate numbers of them practice in certain states or geographic regions?

3. What types of investigatory evidence are being cited in these cases? Are most of the cases based on the prescribing of painkillers in large doses or to large numbers of patients?

4. What kinds of pain medications are being cited in these cases? Are most of these medications oxycodone-based or, more generally, opioid-based?

5. Have most of the physicians involved been charged with criminal rather than with administrative offenses? Are these physicians more likely to end up in a federal or state criminal court than to appear before their state medical board? Do the numbers of criminal or administrative cases of these types appear to be increasing from year to year?

6. Are most of the criminal cases being pursued in federal rather than in state courts? Is there indication that federal prosecutors may be more aggressive in this area than state or local prosecutors?

7. With what specific offenses or violations are the physicians involved being charged? Do most of these charges involve overprescribing? Are many physicians who prescribe controlled-substance pain medications being charged with murder?

8. What are the pleas and verdicts in the criminal cases? Have many of the physicians involved pled not guilty?

9. What types of sentences and sanctions are being imposed on those found guilty? Are many receiving long jail sentences? Are many having their medical licenses or controlled-substance certificates revoked?

10. Do the sentences and sanctions differ according to the level of court or hearing involved? Are federal courts imposing stiffer sentences and penalties on those found guilty than state courts? Are state medical boards less likely to impose fines?

Have many of their cases been either dismissed for lack of evidence or overturned on appeal?

The Center’s Balanced Pain Policy Initiative is also researching in greater detail a small number of cases in which physicians investigated and prosecuted for such offenses involving the prescribing of controlled-substance painkillers have had their cases dismissed, been found not guilty, or have had their guilty verdicts overturned or sentences reduced upon appeal. Findings regarding these “special” cases will help to identify steps that physicians and law enforcement agencies can take to minimize the likelihood that doctors who prescribe strong pain medications will be unjustly accused of criminal offenses.

Don Goldenbaum, PhD, is director of research, evaluation, and publications at the Center for Practical Bioethics, Kansas City, Missouri.
reported moderate or severe pain despite having seen a physician within the previous four weeks.

As a result of these facts, we have an evolving concept of pain as a disease state in its own right. The following real case example illustrates these points and emphasizes the importance for physicians and other healthcare providers to take seriously their professional responsibility to assess and manage pain by understanding its impact on the person.

The patient is a 65-year-old retired African-American man with severe left knee and low back pain secondary to osteoarthritis. He is a candidate for knee replacement, but the degenerative spine disease is nonoperable. The patient has completed multiple courses of physical therapy, including aquatic therapy. He had also had lumbar epidural steroid injections and was being maintained on a pain medication regimen that included OxyContin 20 mg TID with Percocet given as needed for breakthrough pain (averaged 4-to-6 pills per day).

On this regimen, his knee and back pain were not well controlled. However his primary care physician would not increase his medication doses and referred him to a pain management specialist. The pain doctor initially maintained him on the analgesic doses noted above, and began a series of lumbar epidural steroid injections, with only very slight benefit. The patient was referred for a total knee replacement, but his postoperative rehabilitation was compromised because of severe low back pain, which resulted in a less than optimal functional outcome of the surgery.

In the setting of worsening low back pain and untreated constipation, the patient became increasingly socially isolated and depressed, even expressing intermittent suicidal thoughts. He reported less than 50 percent relief of his back pain and only for 6 hours after each dose of medication. Referral to a second pain physician provided an opinion that the patient was “addicted” (although no evidence of abuse, misuse or compulsive use of opioids — the currently accepted hallmarks of addiction behaviors — were observed).

This practitioner recommended a permanent nerve block and gradual reduction in opioid dose, citing concern about his “addiction” and the monitoring of his practice if opioids were continued in the same or higher doses. The nerve block procedure was acutely painful and provided only minimal transient pain relief. Despite this, the patient attempted to discontinue his pain medications because his fears regarding addiction had been reinforced by the (misguided) opinion of the doctor. As a result, his back pain, depression, social isolation, and psychological distress and suffering increased significantly.

Eventually, the patient was rotated to another long-acting opioid (sustained-release oxymorphone), and subsequently reported more than 80 percent relief in pain control, and concomitant improvement in functional status, mood, and social isolation. The benefits of therapy have persisted for more than six months. This patient’s story provides an excellent example of the contemporary issues in chronic pain management. It demonstrates the strong relationship between unrelieved pain, depression, and suffering, and failure to understand that the impact of pain on the person can have devastating consequences.

Cassell (1992) has noted that suffering occurs when a medical condition like uncontrolled pain is experienced as a threat to the integrity of the person and his or her self-identity. The body hurts as a result of the physiological processes related to the painful condition, but the person suffers as a result of the psychological impact of the pain on one’s perceptions of personhood.

“Pain management must . . . include rehabilitation, patient education, and psychological counseling in addition to analgesics.”

The doctors attending to this patient either ignored or minimized his distress and suffering because they focused on pain almost exclusively as a medical problem causing the body to hurt.

Pain management must be practiced with a multidisciplinary approach that includes a focus on rehabilitation, patient education, and psychological counseling in addition to the use of analgesics (Becker et al. 2000). The failure to address seriously the impact

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of pain on this person actually increased suffering and disability and, in that respect, violated the principle of the Hippocratic Oath to first and foremost “do no harm.” The critical point here is that healthcare providers must assess and attend to the impact of pain on the whole person, and not simply treat pain as a medical “problem.”

“Practitioners must hold to the highest standard of competence and knowledge and consider the patient’s need to be more important than their fear of scrutiny.”

This case also illustrates a profound lack of expertise in basic areas of pain medicine, which had the effect of compromising the best interests of the patient and the professionalism of the clinicians involved. Lack of knowledge and errors in judgment were responsible for mislabeling opioid tolerance and physical dependence as addiction, with great adverse consequences for the patient.

Other mistakes included the failure to anticipate and treat common side effects of opioid therapy such as constipation; unwillingness to undertake an opioid titration trial to find the best dose for the patient, that is, one that could achieve the best balance between pain relief and side effects, and the failure (until late in the case) to switch medications to overcome the incomplete cross tolerance between drugs.

All of these treatment options are recommended by widely promulgated evidence-based clinical practice guidelines that were, for the most part, ignored by the clinicians managing this patient.

The case also illustrates the exaggerated fears of addiction on the part of doctors and patients, and also illuminates physicians’ fears of regulatory scrutiny of their prescribing behavior that adversely affect clinical decision-making. One pain specialist in this case commented that he would not prescribe larger doses of opioids for fear that it would be “noticed in Washington.” This is consistent with several reported studies that physicians often prescribe lower dosages or less potent opioids than they would otherwise because of concerns that their practices will be audited by the state medical board or by law enforcement (Clark 1991).

The greatest principle of medical professionalism involves the absolute regard for the well-being of our patients, and for the doctor to act always in a trustworthy and compassionate manner (DeBakey 2004). Healthcare providers have a professional obligation to assess and manage pain and attend to suffering.

This professional responsibility first and foremost requires practitioners to hold to the highest standards of competency and knowledge of modern concepts of opioid pharmacology and pain management. It also involves considering the patient’s needs to be more important than the doctors’ fears of scrutiny of their practice. These fundamental principles of professionalism were violated in this case, and one must be concerned that this patient’s experience did not represent an isolated and rare event.

As Albert Schweitzer famously stated, “pain is a more terrible lord of mankind than even death itself.” Only by practicing with the highest regard for patient-centered caring and according to the highest standards of medical professionalism can we fulfill the premier requirements of our profession, meet the needs of our patients, and discharge our social contract with society.

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Richard Payne, MD, is professor of medicine and divinity and the Esther Colliflower Director of the Institute on Care at the End of Life, Duke University Divinity School, Durham, North Carolina, and an internationally known expert on pain relief, palliative medicine, oncology and neurology.
Bioethics and Pain Management
A Conversation with June Dahl

June L. Dahl, PhD, a professor of pharmacology at the University of Wisconsin School of Medicine and Public Health, Madison, is widely recognized for her knowledge and leadership in pain management. Her teaching, research, and advocacy to improve pain management began more than twenty years ago when she was chair of the Wisconsin Controlled Substances Board. She was a cofounder with David Joranson of the Wisconsin Pain Initiative, and she is an advisor to the Alliance of State Pain Initiatives.

Myra Christopher visited with Dr. Dahl about her work.

1. How did you get involved in research about the treatment of pain?

One factor was my appointment to the Controlled Substances Board of Wisconsin, the state’s drug regulatory authority in the late 1970s. Another was “The Quality of Mercy,” a 1982 editorial by Marcia Angell in the New England Journal of Medicine that changed the way I taught analgesic pharmacology. But the real motivator was heroin. Not the drug per se, but a bill introduced in the U.S. Congress in 1984 to make heroin available to treat pain in persons dying from cancer.

Sponsors of the bill didn’t realize that heroin was no magic bullet, but a controversial and expensive way to give morphine. We had effective drugs and other therapies; the problem was that they weren’t being used appropriately — partly because physicians fear regulators. That knowledge led the Board to form the Wisconsin Cancer Pain Initiative and led me to study ways to remove the barriers responsible for the inadequate treatment of pain.

2. Recently, I was involved in a case consultation in which a pulmonologist referred to pain medicine as “voodoo medicine.” Is there something scientifically different about pain medicine?

Such a comment is very distressing. The practice of pain management is evidence based; it is certainly not derived from myth and magic. I suspect this thinking may relate to a discomfort with the subjective nature of pain, with the fact that there is no device or instrument with which to measure it. We must rely on the patient’s self-report.

Can we believe what patients tell us? How do we know they aren’t looking for a way to get out of a dead-end job? How do we know they aren’t just seeking drugs to get high? Yes, there have been major technical advances (e.g., magnetic imaging) that make it possible to see changes in the activity of the brain of a person in pain, but the results don’t permit the quantification that the skeptics desire.

3. There is a lot of talk about research and development of nonaddictive pain medications. Is there something on the horizon that will replace opioids?

There have been many efforts in the last fifty years to find such a drug. Research led to the synthesis of a class of drugs that are mixed agonist-antagonist opioids. While they are less likely to be abused, they have significant limitations as analgesics. Research has also focused on combining opioids with other drugs to reduce or block their actions if they are taken in ways favored by drug abusers. It has also identified new targets for analgesic drugs, stimulated the study of the neurobiology of addiction, and shown that genetic factors may determine the risk of addiction. Someday there may be new agents to replace opioids, but I believe opioids will play a critical role in pain management for a long time to come.

4. Your career has not been typical of most scientists. You’ve also done policy work, professional education, and patient advocacy. What motivated you to work as you do?

The satisfaction that comes from trying to make a difference in persons’ lives, a reward that I never got from work at the lab bench. Serendipity played a major role as unanticipated opportunities provided motivation, but so has the stimulation from the special people who inhabit the pain world. It has been helpful to look at the issues in this field through the lens of a scientist, to come to them without an agenda based on allegiance to a certain discipline or on myths and misunderstandings that are pervasive in many arenas. I am glad I made the conscious or unconscious decision to take an atypical path.
Too often in clinical practice, I encounter patients who are clearly in pain related to surgery, injury, or disease, but refuse to take pain medications because they “don’t want to get addicted.” Despite overwhelming evidence that untreated pain has deleterious effects on the immune system, tissue healing, tumor growth, mental health and quality of life, individuals will avoid or limit their use of analgesics due to the perceived risk of becoming addicted to the medication.

This fear is echoed in, and reinforced by, the concerns of family members, healthcare professionals, controlled-substances regulatory agencies, and society in general. Referred to by some as “opiophobia” (Morgan 1985), an irrational fear of the potent pain relievers known as opiates persists in our culture, predicated on the erroneous perception that exposure to these medications will ultimately result in aberrant behaviors associated with addiction.

A major issue in understanding the risk of addiction in patients taking opiate analgesics is confusion between the terms physical dependence and addiction. Although these terms are often used interchangeably in general conversation, they are actually quite different phenomena.

Physical dependence refers to biochemical changes that occur in the body in response to the presence of a drug such that when it is suddenly stopped, withdrawal symptoms will emerge. It occurs with opiates as well as with other types of drugs that are not abused (i.e., corticosteroids and certain antidepressants). In other words, physical dependence is a normal response to opiate administration, and since patients naturally wean themselves off these medications as pain improves, withdrawal symptoms are usually not present.

Addiction, on the other hand, is a true neuropsychiatric disorder, evident in aberrant patterns of behavior, and for which treatment is warranted. Increased understanding of the epidemiology and neurobiology of addiction has made clear that addiction is a prevalent and chronic disease of the brain, which, like depression and dementia, has significant consequences on individual, family, community, and public health in general (McGinnis and Foege 1993; ONDCP 2001; WHO 2002). Like other chronic health conditions (e.g., diabetes, heart failure), addiction has a pathophysiological basis, known risk factors, and a predictable course, including exacerbations (relapse). If untreated, addiction will ultimately result in death. Treatments with good efficacy exist and successful management of the disease relies on behavioral changes and social support.
Because it is a disease of the brain in which cortical motivational and behavioral systems are, in essence, hijacked by powerful subcortical memories associated with drug use, the clinical diagnosis of addiction is heavily based in behavioral symptoms. These symptoms include

- adverse consequences associated with use of the substance,
- loss of control over, or the inability to limit, use of the substance, and
- preoccupation with use of the substance to the exclusion of fulfilling social roles.

Thus, addiction is not simply the regular or ongoing use of a drug or substance; it is a characteristic and abnormal pattern of use resulting in significant dysfunction in life activities. In contrast, the patient in pain taking opiate analgesics as prescribed will evidence none of these behaviors; in fact, with adequate pain relief, it is very likely that functionality will significantly improve.

The concern that regular exposure to opiates alone will result in opiate addiction is built on the faulty premise that addiction lies within the characteristics of the drug itself. As with other controlled substances, opiates carry with them a potential for abuse, and in certain individuals, addictive disease will be the outcome of exposure. But the key point is that it is an outcome for only certain individuals. As illustrated in the case of alcohol (another drug with clear abuse potential), only a small proportion (less than 10 percent) of persons exposed to alcohol will develop the addictive disease of alcoholism (SAMHSA 2006). Genetic and environmental factors interact to predispose certain persons (with or without pain) to developing addiction, and clear risk factors (family history of addiction, childhood history of sexual or physical abuse, untreated psychiatric disorders, early age of first use) have been identified and described (NIDA 2007).

Thus, unless he or she has risk factors for addictive disease, the likelihood that a patient taking opioid analgesics for the treatment of pain will become addicted to the medication is low. This finding is borne out in clinical setting on a daily basis, as patients are discharged from hospitals and outpatient facilities having been exposed to, and perhaps physically dependent on, opiates, but without developing addictive disease.

Further, intriguing evidence suggests that while in pain, patients may actually be protected from developing the behavioral manifestations of addiction, or that the addiction liability of opiates is decreased by the presence of pain. Understanding that addiction, a diagnosable and maladaptive pattern of opiate use behaviors, is neither physical dependence nor a likely outcome of opiate use for the treatment of pain helps to dispel fears about the use of opioids in pain contexts, thereby supporting better pain relief and better health outcomes.

References


Peggy Compton, RN, PhD, FAAN, is an associate professor of nursing at the University of California—Los Angeles School of Nursing where she studies pain and opioid addiction from a neurophysiological and clinical perspective. She has written multiple publications on pain management for the patient with addictive disease and assessing for addiction in the chronic pain patient.
To advocate for the homeless, you must first go to the streets. To advocate for improved pain relief — which should be a basic human right — you must go to the person in pain. Breaking through the politics of pain requires more than power, force, domination, or struggle. It requires us to truly understand the place of the person in pain.

What is it like to live in pain? What is it like to be present to those in pain? How can we as healthcare professionals be a moral voice, articulating the outrage of a society that fails to relieve human suffering?

Traditional biomedical ethics offers support for analyzing the problem of unrelieved pain; however, the traditional principles of biomedical ethics — autonomy, beneficence, nonmaleficence, and justice — can also be enhanced by women’s experiences and women’s ways of knowing, being, and doing. Feminist ethics (Welch 2000; Tong 1993) provides an ethics of care including concepts such as nurturance, compassion, and communication.

Our failure to respond to vulnerable people in pain is about power and domination. Feminist ethics challenges patriarchal domination and patterns of power. Feminist ethics applies equally to care of men in pain and to male professionals caring for those in pain. People facing life-threatening illnesses are physically, psychologically, socially, and spiritually depleted. They become frail, vulnerable, broken, and highly dependent on professionals and systems for their basic comfort.

Pain occurs across diseases and settings of care and affects women and men and people of all ages. Still, we can use the paradigm of women in pain to understand the politics of pain. Voices for major reform in pain management have concluded that the failure to relieve pain is a form of violence (Scarry 1985; Ferrell 2005).

The Moral Crisis of Untreated Pain

Unrelieved pain is a form of negligence. It is a moral outrage. It is a failure of systems of education, regulation, and clinical practice to address a common health concern that significantly affects, and sometimes destroys, quality of life (Ferrell, Grant, Padilla, et al. 1991). It is a central component of quality care. Most important, it is a human right.

A few years ago, we conducted a review of fifty leading textbooks in nursing. Our
review of 45,000 pages of text revealed that only 2 percent of the content of any topic related to end of life (Ferrell, Virani, and Grant 1999). The pain content was abysmal (Ferrell, Virani, Grant, Vallerand, and McCaffery 2000).

As a follow up, we held a conference in San Francisco to honor medical and nursing authors, editors, and publishers who had improved their content on this subject. I arrived early in San Francisco, and stumbled upon an antique book shop with several medical and nursing books. I found a medical surgical nursing text from the early 1900s.

I looked up pain and end-of-life care in the index, and I was shocked. This book contained correct information in significant detail. Indeed its message to nurses was that relieving pain was their mandate and part of their essential role. To be a good nurse was to be sure your patient was not in pain. Where then had we gone wrong? In our rush to embrace “progress” over the past decades, had we abandoned our basic professional obligation to ensure that patients are not in pain?

Respect, relationship, and compassion are three essential concepts from feminist scholarship (Farley 2002). Caring for a person in pain requires compassion, and changing the politics of pain requires us to get back to our basic professional obligations. It is one thing to have cancer, quite another to have cancer and pain. It is one thing as a family member to care for someone you love with cancer; it is quite another to care for someone in pain (Ferrell, Rhiner, Cohen, and Grant 1991).

The Body in Pain
Elaine Scarry’s book, The Body in Pain, provides an intimate portrait of the vulnerability of the body in pain. She describes people in pain as often silenced and unable to express their extreme emotion. Pain, she says “resists verbal objectification,” and patients in pain are often disbelieved by both family and professionals. “To have pain is certainty; to hear about pain is to have doubt” (Scarry 1985).

Pain relief is not limited to an end-of-life treatment. Pain begins before diagnosis and is often increased by efforts to cure. In fact, some of the newer chemotherapy agents create more severe pain (e.g., peripheral neuropathy) than the underlying cancer. Pain persists in cancer survivorship. The recent Institute of Medicine report on cancer survivorship noted that there are ten million survivors of cancer (Hewitt, Greenfield, and Stovall 2006). How many of these survivors live in pain? The quality of cancer survivorship care depends on the quality of pain management.

Regardless of how early a cancer is detected, how great one’s prognosis is, or how great our cancer centers are, pain and death in cancer are inextricably associated.

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Beyond Politics – The Patient in Pain . . .

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An important clinical implication of this fact is that cancer patients experiencing pain are inclined to deny their pain to avoid thinking about the possibility of death. As one woman with breast cancer explains:

But when you go to the doctor — when I go to the doctor — the only thing I want to hear is I’m still in remission, no cancer. When they tell me “no cancer” I forget about every pain. I go and have written questions. I have a lot of things I want to say and ask the doctor, why this happened. But as soon as she [the physician] enters, she’ll look at me like this and explain, “Oh, everything’s perfect. Nothing, no problem, no cancer.” And that’s it. I forget all the questions, all the pain. You know what I mean? I leave there, and I’m flying from happiness.

Being with the Person in Pain

Experts in pain management recognize that there are complex dynamics between people in pain and those who care for them. To be fully present with the person in pain becomes an opportunity for respect, compassion, and relationship. Pain relief is not just “doing for”; it is “being with.” The caregiver becomes the therapy, and it is not uncommon for pain to be reduced significantly by the simple presence of a compassionate caregiver.

“Cancer patients experiencing pain are inclined to deny their pain to avoid thinking about the possibility of death.”

University of Wisconsin (www.painpolicy.wisc.edu) and the work of state pain initiatives (www.aspi.wise.edu). These groups are a voice of reason, respect, and compassion. We owe them a great debt for their pioneering efforts to remove this huge and damaging barrier to pain relief efforts.

Despite these efforts, however, the fear of addiction remains significant. A patient with advanced breast cancer said,

No, I don’t have pain. I don’t take any kind of pain killer. Nada. When they prescribe it, I usually don’t take it. I say, “No, it’ll go away.” I’ll either eat something, and it’ll go away, or lie down and it’ll go away, and that’s usually the way it works. . . . Generally speaking, if I’m told to take a pill, I take it. But pain killers are a different issue.

Challenging Voices

Melissa Raphael, a theologian and author of The Female Face of God at Auschwitz (2003), graphically describes the women who cared for fellow prisoners in Auschwitz who were ill, in pain, and dying. She describes the care these women offered as symbolic of “women’s restoration of the human, and therefore the divine.” Perhaps state pain initiatives and other professional organizations that strive to relieve pain can become similar “communities of resistance” and “the sacred face” in healthcare.

Most professionals in pain management are familiar with Margo McCaffery’s assertion that “pain is what the person says it is” (1968), which transformed our field. Prior definitions of pain provided only physiologic perspectives and defined pain only at a tissue level, not a human level. McCaffery’s work challenged pain management the way Carol Gilligan’s In a Different Voice (1982) challenged ethicists’ beliefs about moral development. McCaffery’s work was truly a different voice. She laid the groundwork for respect of people in pain.

I had the opportunity many years ago to attend a national summit on pain sponsored by the American Cancer Society. After two days of discussion focused on barriers to pain relief and ideas for improvement, the meeting ended with each individual voicing what he or she could do. June Dahl stepped forward. “I will call JCAHO and tell them they should require hospitals to make pain assessment mandatory,” she said. Half the group laughed. The rest said “Go, June.” She did it. June Dahl is a moral voice who has led a community of resistance called the American Alliance of Cancer Pain Initiatives.

Advocacy in the politics of pain is hard work. A. M. Jaggar, an ethicist and philosopher who wrote extensively about “outlaw emotions” and the role of understanding, recognized the intense emotions associated with pain (1989). She contends that fear, anxiety, powerlessness, anger, and depression bring us closer to the truth because such emotions are not just a way of feeling but a way of knowing. She recognized pain as an outlaw emotion, unacceptable to society.

Women and Minorities in Pain

The Intercultural Cancer Council (2006) estimates that 65 percent of minority patients with pain, compared to 30 percent of non-minority patients, do not receive adequate analgesics. African-American and Hispanic people, even when diagnosed with serious illnesses, are more likely to be perceived as drug abusers and to be prescribed weak analgesics and smaller doses of pain medications than other patients. These inequities have been documented in several studies of cancer populations, including minority patients in nursing homes (Cleeland 1984; Cleeland et al. 1997; Payne, Medina and Hampton 2003; and Bernabei et al. 1998).
And women, particularly black women in pain, are often overpowered by politics in healthcare settings. A recent study of 1,192 women documented that black women with chronic pain suffer more psychological distress, physical impairments, and post-traumatic stress disorder than white women (Green and Ndao-Brumblay 2005). Thus, another way to understand the problem of pain is to study women in pain. Hoffman and Tarzian (2001) exposed the bias against women in the treatment of pain in their article “The Girl Who Cried Pain.”

The literature on women in pain cites many examples of women who become disempowered, weak, and exhausted from severe pain. To be dependent on a medical system that blatantly disregards pain adds demoralization and doubt to an already consuming experience.

The extensive literature on female pain includes individual narratives of women who become depressed, anxious, and near hysterical as their pain is ignored. These emotions make it even less likely that women will receive respectful care. These pain narratives can be compared to Starhawk’s (1988) persecution narratives of women as witches. Her description of witches as “alienated, powerless, and alone” is very applicable to women with chronic pain who become isolated, powerless, and alone. The “bizarre” behavior of women in pain is punished by a doubting medical community.

Getting relief for pain even as an English-speaking, educated, articulate white woman with insurance can be a challenge. If the patient does not speak English, is poor or oppressed or a member of a minority culture, the chance of adequate pain relief is unlikely. The messages learned from studying women in pain apply to other vulnerable populations.

Tearing Down the Barriers

How can we right this wrong? How do we change an oppressive system? It will change with major systems reforms, laws, regulation, and education. Above all, it will change when we change the culture that allows this system of care to exist. We must begin, as June Dahl and the American Association of Cancer Pain Initiatives (AACPI) began, by becoming a moral voice for untreated pain.

Rosemary Radford Ruether, a leading female scholar and theologian wrote, “...We who belong to this community, however, also have to take responsibility for these mad bombers as our brothers (and sometimes sisters)!”

Who is the enemy? Who are the mad bombers in untreated or undertreated pain?

We need to bring the mad bombers out of the sky and make them stand before the rubble, the charred bodies of the dead, the suffering of the living, and call them into account... We who belong to this community, however, also have to take responsibility for these mad bombers as our brothers (and sometimes sisters)!

Anyone who is silent on the issue of unrelieved pain is part of the politics that has resulted in this public health crisis.

We must break this silence, but, as Ruether also contends, “shifts cannot be done only on the level of technological ‘fixes’ without reshaping patterns of social domination between men and women, and between rich and poor classes and nations.”

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Mary P., a young mother of three small children, is admitted to the local hospital with pneumonia. Six months ago she was involved in a motor vehicle accident and sustained an anoxic brain injury. She also has an arthritic condition that was diagnosed prior to the accident for which she had been taking pain medication two or three times a day.

This hospitalization is the third since her accident. When she is not in the hospital, her husband and family members care for her at home, and the children come to the hospital with their father, who encourages them to interact with their mother. The family states that the patient is able to communicate with them, although no one else sees this interaction.

The nurses on the floor are familiar with Mary P.’s care and her family. The family is devoted to her, but the nurses are concerned about signs of discomfort. In the months since the accident, she has developed multiple decubitis ulcers and contractures. She has no healthcare directive or durable power of attorney.

The nurses talk with the attending physician and request a palliative care consult to address goals of care and concerns about the patient’s discomfort. They often observe the patient with increased respiratory and heart rate, restlessness, and grimace. The husband describes these observations as a result of “being scared.” He says they are not taking enough time to explain procedures. He says he calms his wife by talking to her and stroking her hand. He feels she interacts with him and the children when she is not being medicated, and he wants to give her every oppor-

Questions for Discussion

Reflect on and discuss the following questions with your ethics committee or other colleagues.

1. What facts and assumptions are the patient’s family and clinical caregivers relying on in their effort to determine this patient’s plan of care? Are there other facts to consider? How do we distinguish between the facts and our assumptions?

2. Who is in pain? Is the patient in pain? If yes, is her pain physical or emotional? Who are the stakeholders in this case and what are the values and wishes they bring to their concern for the patient?

3. Does the palliative care team risk its rapport with the patient’s family if it continues to recommend pain medication? Will the patient get the medication when she goes home? What can be done?

4. How does the palliative care team address what the media say about problems of addiction and prescription drugs?

5. Are the family’s goals realistic? Can the patient’s pain be managed? What other goals of care should be integrated in this discussion?

6. What kind of recommendations do you expect from the ethics committee? Reflect on this case, and ask your ethics committee to discuss it in the educational portion of your next meeting.

Case Studies are a regular feature of Practical Bioethics. For more cases, visit www.practicalbioethics.org or ask about our online discussion group. We welcome your response to this case. Please email your comments on this case to bioethic@practicalbioethics.org.

“I want to take her home,” he said, “and care for her myself.”
A Family’s Struggle . . .

(Continued from previous page)

...tunity to wake up and get the best life that she can get. If she is given pain medication, she will not be able to regain her health and interact with her family. He has requested that the primary physician stop all pain medication.

After a discussion with the palliative care team, he agreed to scheduled doses of pain medication. The nurses noted that the patient is more comfortable, with respirations decreased from 30s to mid-20s, no grimace except when turning, and much less restlessness. They see no change in her level of awareness, and no interaction with the family as stated by the husband.

For several days the husband seemed happy with Mary P.’s plan of care and at last she was ready to be discharged. Late one evening the nurse on duty received a call from her husband concerned about what he had heard on a national news program about Oxycontin. He demanded that all pain medication be stopped immediately.

He was concerned about addiction and thought that the healthcare providers had not been honest with him. “I want to take her home, he said, “and care for her myself.”

The Palliative Care Team was dismayed. They had, they thought, built a trusting relationship with the family and wanted to maintain that relationship. They also believed that Mary P. needed her pain medication. They asked the hospital ethics committee to provide recommendations.

Patricia Dalrymple, MSN, RN, is coordinator of the palliative care program at Providence Medical Center, Kansas City, Kansas.

Beyond Politics – The Patient in Pain . . .

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Conclusion

June Dahl helped start a movement: the American Alliance of Cancer Pain Initiatives, which began, like most social movements, with a few dedicated individuals who inspire us to become part of the change. As William Morris said in 1883:

One man with an idea in his head is in danger of being considered a madman; two men with the same idea in common may be foolish, but can hardly be mad; ten men sharing an idea begin to act, a hundred draw attention as fanatics, a thousand and society begins to tremble, a hundred thousand and there is war abroad, and the cause has victories tangible and real; and why only a hundred thousand? Why not a hundred million and peace upon earth? You and I who agree together, it is we who have to answer that question.

References


Morris, William. 1883. “Art under Plutocracy.” Lecture. Published in *To-day* Feb/March 1884.


Betty R. Ferrell, PhD, FAAN, is professor of Nursing Research and Education and a Member of the City of Hope Comprehensive Cancer Center at the City of Hope Medical Center, Duarte, California.
A Patient’s Perspective . . .
(Continued from page 2)

For several years, the Center for Practical Bioethics has been involved in a project with the Federation of State Medical Boards and the National Association of Attorneys General. This project seeks to improve the undertreatment of pain by finding factual, research-based answers to key questions about the diversion of prescription drugs. Donald Goldenbaum from our staff writes about this project in “Restoring Balance to Pain Treatment Policy” (this issue, p. 3-4).

Ironically, a little more than a year ago, I became a patient with chronic pain. Due to bilateral osteoarthritis and nerve pain associated with deteriorated disks, I now experience many of the problems our authors have described so tellingly. My perspective on pain has, not unexpectedly, shifted yet again.

I have always described myself as “healthy as a horse.” At one point, I even boasted – foolishly – that I had not seen a physician as a patient for more than a decade. But my life changed dramatically near the end of 2006, when I began having excruciating pain in my left leg below my knee.

When I finally met with the pain specialist, I was left with “I thought I was losing my mind.” At one point, I even boasted – foolishly – that I had not seen a physician as a patient for more than a decade. But my life changed dramatically near the end of 2006, when I began having excruciating pain in my left leg below my knee.

I saw my internist and an orthopedic surgeon. We talked about a knee replacement, but I had had “bad knees” for years, and this sensation was a different kind of pain. I took a variety of pain medications and had steroid injections in my knees. Nothing we did helped.

Finally, I was referred to a pain specialist. On the day of my first appointment with her, I could hardly walk. I could no longer put weight on my left leg. When the nurse who took my history asked me if I was familiar with the pain scale, I nearly bit her head off. When she asked me what my goal was — that is, “how much pain I wanted to live with” — I thought I was losing my mind. When I finally met with the pain specialist, I was sobbing. I hadn’t cried like that in front of anyone since my mother died nearly 30 years ago. I felt desperate, hopeless, and I was in excruciating pain.

Since then, I have been on what I think of as high doses of opioids, and I have had a series of lumbar epidural steroid injections. I have been trying to swim and walk in water as often as I can. For a while I was much better, but now the pain is creeping back. In addition to being in pain, I am feeling unsettled and discouraged and I worry that I may have exhausted my options. I am feeling frightened, and I do not know what to do.

I had hoped for a miracle, but as our authors will tell you, pain cannot be willed away. Instead, research is needed to provide more data and more insight into the mechanisms that underlie pain and more understanding of the ethical, clinical, and legal obstacles that pain specialists and their patients encounter in their effort to recognize and treat the person in pain.

In September, I have been invited to speak on these issues with Karen Tandy, administrator of the U.S. Drug Enforcement Administration. I hope I will feel like traveling to Washington.

Myra Christopher

Myra Christopher is president and CEO of the Center for Practical Bioethics. For more information about the Center or the balanced pain policy initiative, see www.practicalbioethics.org.