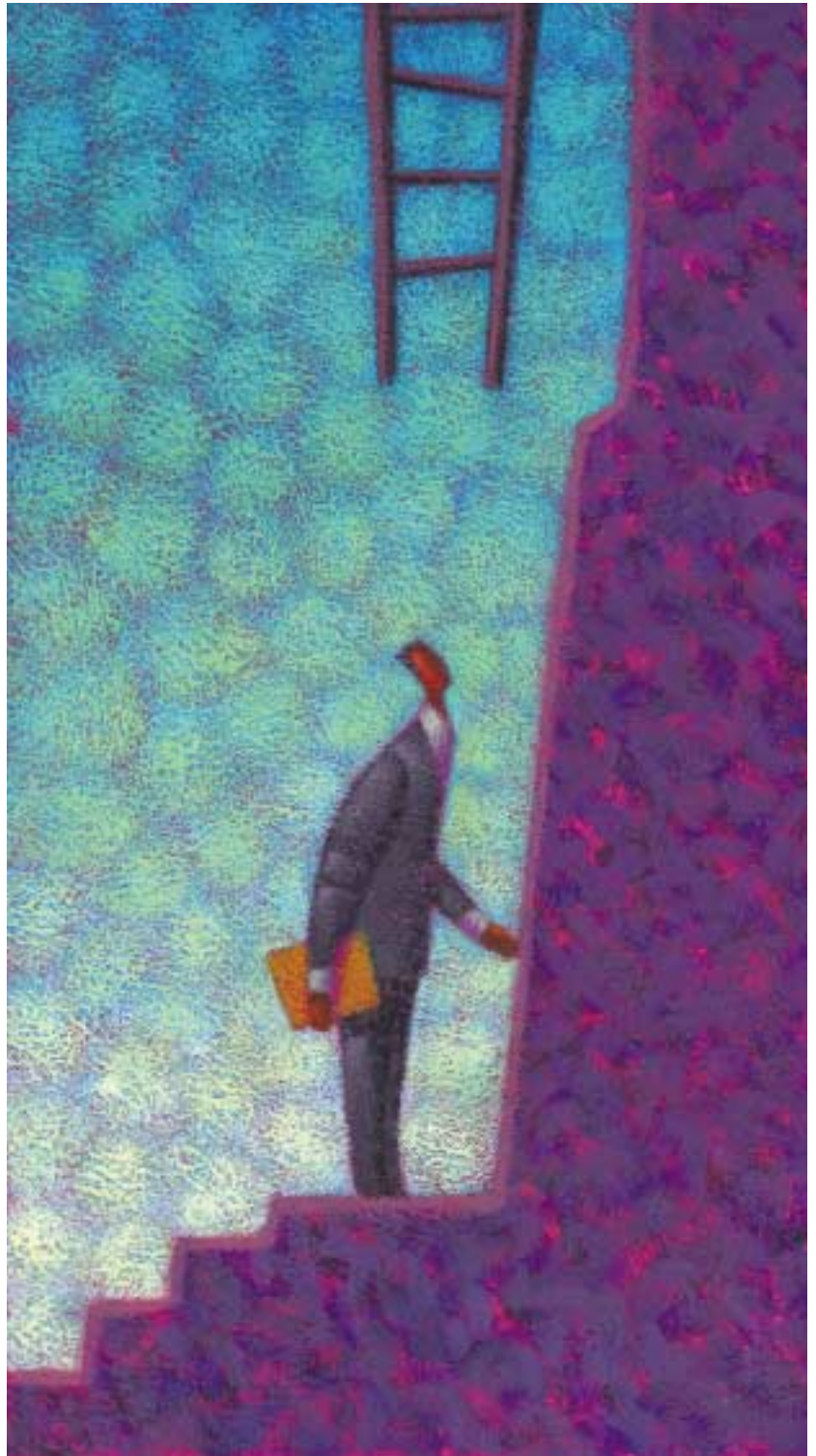


# *Obstacles* to Effective Pain Man

**by Yvette Colón, M.S.W.  
and Carol Harper, M.A.**





# agement

## in Patients with Cancer

**M**isconceptions about pain are widespread among patients with cancer and all too often lead to inadequate pain management. Many patients believe that pain is inevitable, pain builds character, opioids are addicting, and complaints about pain distract the physician. Often patients with cancer are reluctant to report pain to their doctors because they are afraid the pain means that their cancer has worsened or they will be labeled “a bad patient.” Some patients believe that living stoically with pain is a sign of strength and acknowledging pain or seeking help is weak.

Many patients with cancer are not aware that they have the right to have their pain assessed and managed appropriately, and many lack education about pain management options.

Serious pain is a family issue, affecting the patients' relationships with partners, family, and friends, and interfering with daily activities and life goals. Families and friends often have their own reactions to a patient's pain and struggle with cancer. Patients must deal with these reactions in addition to coping with their physical condition. Loved ones may want to be helpful and supportive, but if they do not understand what the pain is like or the pain's effect on the patient's physical and mental well-being, they can make the situation more difficult. Counterproductive responses from family members can range from ignoring the patient's concerns and complaints to becoming angry with the patient.

Such misconceptions and difficult responses are just two of the many barriers that are responsible for most cancer pain being undertreated or not treated at all, despite the fact that pain can be relieved or greatly eased with proper pain management.

Proper pain management requires that patients receive clear and consistent messages, follow-up, and follow-through from the treating team to be sure that the pain management regimen is working. From the patient's perspective, a pain management plan involves the physician who prescribes the medication, the nurse who gives instructions on how to take the medication, the social worker who helps the family feel more comfortable with the medication, and the pharmacist who actually dispenses it. Because these players are often not in the same room at the same time, consistent messages for the patient are sometimes hard to achieve. Unlike a baseball game where everyone is on the field, a pain management plan is more like a relay race where critical information is handed on at certain points. In the end, the goal is still the same: effective pain management for the patient.<sup>1</sup>

### Who Is at Risk for Inadequate Pain Management


Certain groups of patients are at high risk for inadequate pain management. Rural patients may not have access to pain specialists or pain clinics. Elderly people may view pain as an inevitable part of aging, and some older patients may have medical or cognitive conditions that prevent them from describing their pain or following a pain management plan. Ethnic minorities and people in lower income brackets are often uninsured and have difficulty obtaining health care.

Compelling evidence exists that minorities receive lower quality health care than Caucasians. Even when factors such as insurance status, income, age, and severity of condition are comparable,<sup>2</sup> minority cancer patients are at two to three times the risk of inadequate pain management. Factors responsible for this disparity may include cultural differences between providers and patients, language barriers, and the shorter length of time physicians spend with minority patients.

Minority patients may also mistrust the health care system because of traumatic past experiences. A study by van Ryn and Burke<sup>3</sup> found that physicians had negative stereotypes about African Americans and people of low socioeconomic status. Physicians estimated their patient's intelligence, their likelihood of engaging in risk-taking behavior, and their ability to adhere to medical advice based on their race.<sup>3</sup> The patient's socioeconomic status was associated with perceptions about personality, abilities, and behavioral tendencies.<sup>3</sup>

Gender is also an important factor. Cleeland and colleagues<sup>4</sup> found that being female was a significant predictor of inadequate pain management. A study by Calderon<sup>5</sup> in 1990 suggests that inadequate pain management for women may be due to the perceptions that women complain more, do not accurately report their pain, are better able to tolerate pain, or have better skills to cope with pain than men do. The fact that women are overrepresented in certain conditions associated with pain such as fibromyalgia and temporomandibular joint disorders is also a contributing factor to inadequate pain management.

Although religious beliefs such as “I deserve this,” “God is punishing me,” or “God has abandoned me,” may have a deleterious effect on a patient's perception of pain, Keefe and colleagues<sup>6</sup> found that patients who used religion or spirituality to cope with the chronic pain of rheumatoid arthritis increased their sense of well-being, decreased their pain, and reported higher levels of emotional, social, and disease-related support than patients who did not use religion or spirituality to handle this problem. The study suggests that understanding a



# Most physicians and other health care professionals have not received training in pain management...

patient's religious and spiritual beliefs is critical to understanding their pain experience.

Cultural differences also affect the experience and perception of pain. Since a patient's ideas about why they are suffering will affect the course of a pain management plan, cancer care professionals must be aware of subtle cultural variations in language, verbal and nonverbal communication, and expressions of distress, and must understand the effect of ethnicity on the daily life of patients and their families.

## Lack of Training and Poor Communication

Most physicians and other health care professionals have not received training in pain management and are not comfortable seeing patients with chronic pain. The low priority that medical schools and residency programs give to pain treatment contributes significantly to inadequate pain management.

A physician's inability to assess pain properly is an important cause of inadequate pain relief, especially in patients with cancer. If practitioners do not have adequate pain assessment tools, know few alternatives to prescribing opioids, or are hesitant to even prescribe opioids, their patients will not have adequately controlled pain.

Good communication between physicians and their patients is the cornerstone of effective pain management. Physicians who have difficulty with pain management cite the subjectivity of their patients' pain reports and lack of time as two of the biggest impediments to good communication on this difficult subject.

Pain assessment by patients runs the gamut. Some patients are fully functional but say their pain is an 8 on the 1 to 10 point pain scale. Other patients report their level of pain is 2 or 3 when they are obviously in pain and their families report they are no longer able to get out of bed every day because of the pain.<sup>7</sup>

Pain is the most feared complication of cancer, and yet some patients stop taking medication because, for instance, it constipates them. Instead of reporting this side effect and asking for a remedy, they just stop taking the medication.<sup>7</sup>

Clinicians see patients who are stoics as well as others who are hypersensitive to and/or afraid of pain. Because pain is a subjective experience, clinicians must use multiple pain-measuring tools to accurately assess how much a patient's life is affected by pain. Although these assessments take time and are rarely reimbursed, they give the physician part of the information needed to provide pain relief.

Because pediatricians tend to depend on third parties for information, pediatric cases present another set

of communication challenges. Medical schools try to teach pediatricians to listen to children as well as their parents. Although physicians assume that children cannot accurately describe their pain, "ouch charts," or even a simple "show me where it hurts" can bring an amazingly detailed statement from a child.<sup>8</sup>

When clinicians have developed some comfort level with the family and the diagnosis, direct communication with the child can be the best source of information for controlling that child's pain. Remarkably, children can use patient-controlled anesthesia just as adults do if they can communicate well with their pediatrician.<sup>8</sup>

Pain assessment tools help caregivers establish a baseline pain level, and also make evaluating what is happening in the patient's body easier when pain levels or locations change. A review of some available pain assessment instruments will be available in the September/October 2003 issue in an article entitled, "Pain Management: Physical, Psychological, and Spiritual Issues."

## Barriers to Using and Obtaining Opioids

Stigmas associated with opioids and other powerful painkillers present another barrier to effective cancer pain management. Although some patients cite potential addiction as a reason for rejecting painkillers,<sup>9</sup> research has found that opioids decrease pain and improve mood without causing addiction.

Taking legal, FDA-approved opioid medications for pain relief (under the direction of a physician) is safe and effective, and only in rare cases leads to addiction.<sup>10</sup> When properly used, opioids rarely give a "high"—they give relief. And, most importantly, these medications allow many people to resume their normal lives.<sup>9</sup>

The Controlled Substances Act (CSA) is the best example of a federal law that originated in response to drug diversion and abuse and now affects the ability of physicians to prescribe opioids for pain relief. The CSA requires all handlers of controlled substances to be registered and tracked, and has other provisions to make sure that these medications are only used for legitimate medical purposes.

State laws concerning controlled substances vary widely and can be unclear. Many states limit the amount of a controlled substance that can be dispensed at one time, so physicians have to write weekly prescriptions for patients who need large doses of pain medication.

In states with cancer pain coalitions, efforts are being made to rewrite legislation and remove barriers (such as dosage restrictions) on the use of opioids for cancer pain. A 1990 revision to the CSA mandates that if state statutes use the words "addict," "drug abuser," and/or "drug dependency," the definitions must clearly

## Pain Care Bill of Rights

As a person with pain, you have:

**The Right** to have your report of pain taken seriously and to be treated with dignity and respect by doctors, nurses, pharmacists, and other health care professionals.

**The Right** to have your pain thoroughly assessed and promptly treated.

**The Right** to be informed by your doctor about what may be causing your pain, possible treatments, and the benefits, risks, and costs of each.

**The Right** to participate actively in decisions about how to manage your pain.

**The Right** to have your pain reassessed regularly and your treatment adjusted if your pain has not been eased.

**The Right** to be referred to a pain specialist if your pain persists.

**The Right** to get clear and prompt answers to your questions, take time to make decisions, and refuse a particular type of treatment if you choose.

*Although not always required by law, these are the Rights you should expect, and if necessary demand, for your pain care.*

©American Pain Foundation; [www.painfoundation.org](http://www.painfoundation.org); 888-615-PAIN (7246)

*of consumer information, at the American Pain Foundation. The foundation is an independent, nonprofit organization serving people with pain through information, education, and advocacy.*

### References

<sup>1</sup>In a conversation with Kathryn M. Smolinski, M.S.W., cancer pain and fatigue social work fellow at the Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins, Baltimore, Md., July 2002.

<sup>2</sup>Smedley BD, Stith AY, Nelson AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington DC: Institute of Medicine; 2002.

<sup>3</sup>Van Ryn M, Burke J. The effect of patient race and socio-economic status on physicians' perceptions of patients. *Soc Sci Med*. 2000;50(6):813-828.

<sup>4</sup>Cleeland CS, Gonin R, Hatfield AK, et al. Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med*. 1994;330(9):592-596.

state that these terms do not apply to patients who are legitimately using prescribed controlled substances.

The effort to prevent diversion and drug abuse must not keep opioid pain medications out of the reach of pain sufferers. On both a national and a grassroots level, pain management advocates are working with drug enforcement agencies to ensure cancer patients can access the help they need to ease their suffering.

Another barrier is that HMOs and other managed care entities have utilization review boards that monitor and restrict the use of controlled substances and require a constant flow of paperwork to ensure continuity of treatment with these drugs.<sup>11</sup> Often the boards are not staffed by medical professionals but by administrators following sets of rules or guidelines.

Finally, both HMOs and third-party insurers usually do not allow the dose of a controlled substance to be increased after an initial prescription is written. This restriction fails to account for cancer patients who may suffer from rapidly advancing disease and often require numerous dosage changes. ■

*Yvette Colón, M.S.W., is director of education and Internet services, and Carol Harper, M.A., is manager*

<sup>5</sup>Calderon KL. The influence of gender on the frequency of pain and sedative medication administered to postoperative patients. *Sex Roles*. 1990;11-12:713-725.

<sup>6</sup>Keefe FJ, Affleck G, Lefebvre J, et al. Living with rheumatoid arthritis: The role of daily spirituality and daily religious and spiritual coping. *J Pain*. 2001;2(2):101-110.

<sup>7</sup>In a conversation with Gary Cohen, M.D., chairman of oncology at Greater Baltimore Medical Center, Baltimore, Md., June 2002.

<sup>8</sup>In a conversation with George Dover, M.D., chair of the Johns Hopkins Children's Center, Baltimore, Md., June 2002.

<sup>9</sup>Chronic pain in America: roadblocks to relief. Survey conducted for the American Pain Society, the American Academy of Pain Medicine, and Janssen Pharmaceutica. Hanson, NY: Roper Starch Worldwide, 2000. Available at: [http://www.ampainsoc.org/whatsnew/toc\\_road.htm](http://www.ampainsoc.org/whatsnew/toc_road.htm). Accessed on July 23, 2002.

<sup>10</sup>In a conversation with James Campbell, M.D., professor of neurosurgery at Johns Hopkins Medical Center, past president of the American Pain Society and chair of the American Pain Foundation, May 2002.

<sup>11</sup>Max M. Improving outcomes of analgesic treatment: Is education enough? *Ann Intern Med*. 1990;113:885-889.