Social, Cultural, Spiritual, and Psychological Barriers to Pain Management

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Chapter 4

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By Kenneth J. Doka

Introduction

In 1986, a statement from the World Health Organization (WHO) asserted, “Nothing would have a greater impact on improving cancer pain treatment than implementing current knowledge” (Herr, 2004). Sadly, 20 years later, that statement is no less true.

There is a powerful paradox in pain control. In the past 30 years, there has been extensive and worldwide growth in hospice and effective end-of-life palliative care. Pharmaceutical and other pain management strategies have been developed so that few people need experience extensive pain at the end of life. Yet, the reality is that many people die in pain every day (Bernabei et al., 1998).

How do we explain this paradox, especially in countries such as the United States, which would seem to have all the resources needed to provide good palliative care? The fact is that while the technology for pain control is there, there are many complex and interrelated barriers to effective pain management at the end of life. These barriers include social, spiritual, cultural, legal, regulatory, and educational obstacles to pain
control. The barriers affect and impede not only physicians and other health care workers but also patients and their families.

A cultural gap exists in pain management: We know far more about the control of pain than we have effectively been able to incorporate into regular medical practice. This chapter explores that gap, identifying six types of barriers to effective pain control. The hope is that by identifying these obstacles we can overcome them and fully realize the vision of the late Dame Cicely Saunders, the founder of the modern hospice movement, who believed that people need not die in pain.

**BARRIERS TO PAIN MANAGEMENT**

**Social Barriers**

Since the early years of the 20th century, the government of the United States has actively sought to control the illegal use of certain drugs, such as opioids. This campaign has left the general population with a deep-seated negative impression of opium and opioid drugs. The use of such drugs carries a strong social stigma and opprobrium that leaves even those who need relief from constant terminal pain reluctant to turn to such pharmaceutical remedies. In an era when we are urged to “just say no,” it is often difficult to say “yes” to opioids, even when there is a legitimate purpose for using them. In short, the general social climate looks at the use of drugs as a mark of weakness of character. The result is that even people in terminal pain (and their families) would rather tolerate pain than use medications that carry such a stigma.

The so-called “war on drugs” has not left the medical profession unscathed: Physicians may share the negative outlook. It is not unusual for physicians and other care providers to suspect that a patient who claims to be in pain even after being treated for an underlying condition may be a potential or active drug abuser (Hill, 1993). This attitude may persist even though the experience of pain is quite subjective and tolerance of pain medication varies among individuals.

Beyond the general social climate, physicians worry about the regulatory and legal implications of prescribing opioids. These drugs are highly regulated and controlled, and physicians know that the heavy use of opioids can call attention to one’s practice. While this is more of an issue in
chronic than in terminal care (especially hospice care), it still has a chilling
effect. The restrictive regulatory and legal climate has generated calls
to increase the availability of drugs, including opioids, to manage pain
(Dilcher, 2004). Even the National Association of Attorneys General has
recognized the need to assess the extent to which federal and state policies
regulating controlled substances can inhibit pain management.

An additional social factor creates a barrier to pain management:
income. It is well established that income generally affects access to
all aspects of health care, including hospice and palliative care (Boyd &
Clayton, 2002). Lower income persons are less likely to use hospice services
and more likely to report pain at every level of care.

There are many reasons for this discrepancy. Lower income persons
generally have fewer available health care alternatives. They may not know
about medical alternatives such as hospice or about their right to receive
these services. Lack of a primary care physician and dependence on clinics
and emergency rooms may make it more difficult to offer and coordinate
such services (Green, Baker, & Nday-Brumblay, 2004).

Other implications of social class and income may be subtler. For
example, there is likely to be a significant social and educational disparity
between physicians and lower income clients that may impair communica-
tion. Lower income clients may be afraid to assert themselves, unable to
advocate when interacting with physicians, and more likely to respond to
the physician’s sense of authority. On their part, physicians may suspect
that a lower income patient who constantly complains of pain and seeks
opioids may, in fact, be a potential abuser.

**Cultural Barriers**

Another set of barriers to pain control is cultural. Since the 1965
Immigration Act, American society has become increasingly ethnically and
culturally diverse, with increasing immigration from Asia, Africa, and
South America. Cultural diversity can affect pain management in a number
of ways.

There is some evidence that the very experience of pain may differ
among cultures. Early research by Zborowski (1952) suggested that pain
thresholds themselves might differ among cultural groups.
Beyond possible differences in pain thresholds, culture can create barriers in two ways. First, it may be difficult to effectively assess pain in persons of another culture. Pain is a highly subjective and individual experience, and it is never easy to assess another's experience of pain. The difficulty of assessing pain can become infinitely more pronounced when communicating across cultures. In certain cultures, pain is met with stoicism, so a lack of verbal or behavioral expressions of pain may not mean that the pain does not exist. In other cases, persons of different cultures, especially when English is not the first language, may not fully adhere to pharmaceutical treatments because they do not fully understand the instructions (Juarez, Ferrell, & Borneman, 1998).

Second, culture may influence adherence to pain management regimens. Persons from different cultures may have their own beliefs about the significance of pain, symptoms, treatment, and even the very meaning of disease. For example, Fadiman (1997) describes the cultural clash that occurred when American physicians sought to treat a Hmong child suffering from epilepsy. Her family was at first confused and nonadhering, because the medications prescribed seemed to make the child ill. More important, they were ambivalent about the treatment. In Hmong culture, epilepsy is considered a deeply spiritual experience; the epileptic is a highly honored, chosen conduit to the spiritual world. This story illustrates the fact that, to treat a person effectively, health care providers must be sensitive to the individual's cultural experience of illness.

This is true in pain management as well. Cultures may have their own beliefs about the importance and meaning of pain and their own folk remedies. The sensitive health care provider tries to understand these perspectives and, when possible, use them as adjuncts to treatment.

Again, physicians need to be aware of their own biases when they approach members of different cultures. Cultural differences can color assessments of the veracity and validity of the patient's pain complaints.

All of these social and cultural factors can interact. For example, Anderson et al. (2000) found in their study of economically disadvantaged African-American and Hispanic cancer patients that both groups were undertreated for pain by their physicians, and that undertreatment was most pronounced for female patients.
**Spiritual Barriers**

Pain and suffering have always been part of the human condition, and every faith and form of spirituality has addressed the question of why humans experience pain and suffering. The answers have varied. To some, suffering and pain are experiences that tie an individual to the whole of humanity; so to deny pain is to deny being human. As Moller writes:

> The normative medical response to pain is to demand more drugs, doctors and hospitals.... If humanity is deprived of the capacity to suffer, then it embarks on a path which narrows the experience of being human (1986, p. 129).

To others, pain is a mystical experience, one that brings the individual into a deeper connection with God. Still others see pain and suffering as retribution for acts committed in this or previous lives. To these believers, to deny pain is to fail to fulfill the tasks inherent in life and, thus, be doomed to repeat them in some future life or suffer in an afterlife. Aries (1981) reminds us that in the Middle Ages sudden death was most feared, as it deprived the individual of an opportunity to repent for his or her sins. Severe pain had value: Not only did the suffering motivate the individual to become right with God; it also lessened the time he or she would have to spend in Purgatory (where one was purged of sin as one awaited acceptance into Heaven).

In some belief systems with dual or multiple deities, pain might be attributed to the more malign spirit. In other systems, pain may be considered a warning from God or a path to new understanding or insight. Even many people with a nontheistic belief system see pain in the latter light. Fertziger (1986) makes no direct theistic reference as he asserts that pain at the end of life is the crucial link between death and growth. This widely held belief (an instrumental view of pain) emphasizes that pain is an essential instrument of growth. Without pain, there can be no change. Consider how pervasive this view is: It can be found all the way from Marxist theory, which holds that the suffering of the masses is essential for revolution, to the signs in a gym that proclaim “No pain, no gain.”

Other spiritual belief systems affirm that pain is simply “fate,” over which humans have little, if any, control. And some people believe that pain
is simply a mystery—there is no answer to why we experience pain and suffering; we just do.

The point is that every individual—and, for that matter, every health care provider—has spiritual beliefs about the nature of pain and suffering. In many cases, these beliefs may include a perceived spiritual benefit to experiencing pain or suffering. It is essential to understand and assess these beliefs to provide effective pain management, as they may impede the delivery of pain relief.

**Personal and Familial Barriers**

While spiritual beliefs may interfere with effective pain management, other beliefs, knowledge, and attitudes held by the patient or by family caregivers also may inhibit pain control. Pain is subjective, and the only way it can be treated is if it is appropriately assessed. Thus, pain may not be effectively treated if conscious and aware patients either do not report or minimize their experience of pain.

There may be many reasons why patients do that. They may have fears about pain control. They may worry that pain medications will cloud their judgment, reduce their independence, or limit their level of consciousness. An Australian study, for example, found that older patients strongly wanted their physicians to explain options about pain management and actively involve them in developing regimens to control pain (Lansbury, 2000).

Patients also may be reluctant to admit to pain. They may believe that a good patient accepts discomfort and does not complain or that, in any case, effective management of the pain may not be available. They may harbor, even at the end of life, fears of addiction. There may be a social class or generational factor here as well: Patients who were less educated, reported lower income, or were older were more likely to hold these beliefs (Ward et al., 1993).

Other fears may need to be addressed. Patients may fear that the drugs will cause opioid toxicity; that is, they may fear the implications of regularly taking drugs that are often portrayed as dangerous. The multiple warning labels placed on such drugs, designed to discourage inappropriate use, may feed these fears (Bressler, Geraci, & Schatz, 1991). Patients may worry about tolerance, fearing that they will need to increase the dosage to levels that will be incapacitating. They may be fearful of procedures
(unsure of dosages or fearful of injections) or worried about the implications of drug use. In short, many patient-related barriers may interfere with pain management (Dawson et al., 2005).

In addition to fears and lack of knowledge, patient attitudes must be considered. Patients may believe that it is a mark of courage and tenacity to die without medication. In Harper Lee’s classic novel *To Kill a Mockingbird* (1960), there is a rather unpleasant character named Mrs. Dubose. At one point in the book, Jem Finch, the teenage son of the central character, has to read to this dying woman. To Jem, the experience becomes increasingly strange. Mrs. Dubose always begins by taunting and berating him, then falls into a strange silence. Later, Jem learns that, as she died, the old woman was attempting to break her illness-related addiction to morphine. Her decision to die in pain is cast as a great act of personal courage; a lesson in bravery for Jem and his sister Scout.

Some patients may be said to have the “Dubose syndrome”—a desire to die without medication, even if this decision results in a painful death. While this may be a legitimate choice by a patient with the capacity to make such a decision, it should always be assessed and discussed.

These fears, attitudes, and misinformation may exist not only in patients but in their family caregivers as well (Letizia, Creech, Norton, Shanahan & Hedges, 2004). In fact, the importance of caregiver beliefs and attitudes is magnified at the end of life, when they may be the primary administrators of pain medication and, in some cases, the primary source of information on the patient’s pain.

**Physician and Health Care Provider Barriers**

But the major barriers to pain management rest with physicians and health care providers rather than with patients and their families. Dawson et al. (2005) found that while patients’ beliefs were a factor in the effective management of pain, it was the health care providers’ pain management behaviors that were most predictive of pain relief. Even with resistant patients, physicians and other health care providers could generally prevail. The paradox of pain management is most evident here: The tremendous increase in knowledge and resources to control pain has not effectively translated into medical practice (Weinstein et al., 2000).
This situation is partly owing to bias or, as Weinstein et al. term it, “opiophobia”—prejudice against the use of opioid analgesics. Beyond this bias regarding the use of opioid analgesics, physicians also may hold negative views regarding patients who constantly complain of pain (Weinstein et al., 2000). Often, too, they perceive that high dosages of opioid analgesics will attract unwelcome regulatory scrutiny of their practices (Hill, 1993).

It is not just bias, though; education is also a factor. The new Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards emphasize pain management, but many physicians and other health care providers were educated at a time when pain management and palliative care were not emphasized. Many providers lack skill in pain assessment or knowledge of the need to individualize the treatment of pain on the basis of the patient’s profile. Many professionals may not understand appropriate analgesic regimens or the routing of dosing. Physicians and other health care providers lack information on standards and procedures for treating pain (Hill, 1993; Tarzian & Hoffmann, 2005; Weinstein et al., 2000). Some health care providers are uncomfortable administrating pain medication, fearing that they might overdose a patient (Tarzian & Hoffmann, 2005). Moreover, physicians and other health care providers may be confused and may find it difficult to differentiate among addiction, physical dependence, and tolerance (Weinstein et al., 2000). These factors further complicate the assessment and treatment of pain.

This kind of confusion, especially at the end of life, has led to perceived ethical dilemmas. Health care providers often struggle with such ethical concerns as euthanasia, assisted suicide, and terminal sedation; they are unsure of where moral boundaries could be drawn and confused about how their attempts to manage pain might be perceived (Ferrell et al., 2001).

**Structural Barriers**

The current structure of medical practice militates against effective pain management. Medical care, especially in the United States and other industrialized nations, is highly specialized. Dying persons, especially older persons, may have multiple chronic conditions for which they are seeing various specialists. Even within the treatment of one illness, patients may see multiple specialists. Furthermore, a patient may be treated in different settings—home, hospital, and nursing home—further limiting
the continuity of care. The result is often a fragmentation of care. No one physician holds primary responsibility for the patient and his or her pain. Outside of hospice, multidisciplinary teams to manage pain are rare (Gaijchen, Blum, & Calder, 1995).

This fragmentation of care limits the communication between physicians and patients. Patients may not know their specialists very well. Even more critically, the physician may not know the patient, which further complicates the assessment of pain (Redmond, 1997). Fragmentation also can inhibit appropriate referrals to hospice, the institution most skilled in symptom control and pain management (Tarzian & Hoffmann, 2005).

There may be other structural difficulties as well. Pain may not be consistently kept track of (Redmond, 1997). Because opioids are so highly regulated, health care organizations may create additional procedures to document their prescription and administration. Such procedures may create a lack of flexibility and increase the time and work needed to administer pain medications, further impeding pain management (Carr, 1997; Redmond, 1997). These problems are exacerbated in facilities that suffer from ineffective or inconsistent leadership or poor working relationships among health care staff (Brockopp et al., 1998).

**Easing the Pain: Suggestions for Practice**

Advances have been made in easing the pain of persons at the end of life. The development and growth of hospice over the past 30 years is a substantial accomplishment. Hospice has not only brought a vision to the public of living comfortably to the end of life; it has spawned both pharmaceutical and nonpharmaceutical strategies for alleviating pain and has modeled interdisciplinary and holistic care to treat pain. In fact, the growth of the hospice movement has generated a greater interest in palliative care.

There have been other advances as well. The WHO has made cancer pain relief one of its top priorities for research, education, and advocacy (McCaffery, 1992). The new JCAHO standards emphasize to hospitals and health care providers the primary importance of pain management. The efforts of the National Association of Attorneys General have called attention to the ways that regulatory practices and policies may inhibit the effective management of pain, possibly leading to changes in the overall regulatory climate that influences pain management.
Yet, much remains to do. Continued research is a major priority. That research should not only seek to develop new pharmaceutical methods of pain management but should also assess nonpharmaceutical and complementary approaches to pain control, the advantages and drawbacks of various routes of administration of pain medication, and the effectiveness of various strategies of pain management. For example, the notion of “pain ladders,” in which one moves from one level to another, has been challenged with the suggestion that it may be necessary to “skip steps” after assessment to allow more timely and effective pain management. Obviously, research will be necessary to establish the claims of these different approaches to pain control. Pain research also should clearly evaluate pain management strategies and the effectiveness of medications on underserved populations such as older persons, women, and children. Psychosocial research is also needed. Training for health care providers in pain management, techniques for consumer education, and approaches to improving communication among health care providers, family caregivers, and patients all need to be developed and evaluated.

Research alone, though, is not enough. Pain management must be infused into the education of physicians, nurses, and other health care providers. Such training should include knowledge of the varied pharmaceutical and nonpharmaceutical approaches to pain management and the strategies to administer drugs. It should also strengthen the skills that enable physicians, nurses, and other health care providers to assess pain in patients. Skills training can range from a simple reminder that rephrasing a question from “Are you in pain?” to “Are you comfortable?” can yield more information to training in sophisticated approaches to assess and manage pain in populations such as persons with developmental disabilities or dementia. Physicians can be taught to include patients and families in an experimental ethos. Patients and families may be willing to try strategies that are clearly explained as trials, especially if they know that they will have a role in evaluating whether or not these medications will be continued. Training also should allow health professionals to confront their own biases that might affect pain management, including a reluctance to use opioid analgesics or discomfort with patients from other cultures or social classes.
Training of health professionals should include tools to help them approach patients and their families. Patients and families share responsibility for pain control; in fact, patient self-reports are the most important tools in pain assessment. When the patient is incapacitated, the observations of family caregivers are essential. The fears and concerns of patients and families may offer considerable barriers to effective pain management. Physicians, nurses, and other health professionals need training and supervision in communicating with the patients and their families and involving them in pain management.

Training is needed at all levels. Often, it is the home health aide or the nursing assistant who has the closest relationship with the patient and, thus, is the most suitable person to assess pain. Often, it is the aide who administers and monitors pain medication. The overall process of pain management will work best if these medical personnel are well-trained and valued.

Patient and family education is essential. Patients and family caregivers may need to be educated in ways to assess pain and administer medications. They may need to learn to be pain advocates for themselves or a family member. This process works best when patients and families have adequate training and are respected by health professionals.

But pain management is not just about individuals; systems will need to change as well. Pain management is the responsibility of everyone on the health care team. Many dying patients have multiple diagnoses and chronic conditions, so pain must be managed across medical disciplines and specialties. Unfortunately, especially in hospitals and nursing homes, systems may not facilitate or even allow such cross-communication. An emphasis on education would encourage communication across disciplines and specialties.

Hospitals, and sometimes nursing homes, often have one element that can take a more active role in pain management: the ethics committee. Ethics committees can help in three ways. First, they can encourage consultation among health professionals on pain management issues, even sponsoring grand rounds on the topic. Pain management and ethical concerns intersect at the end of life, especially in areas such as terminal sedation or fears (often needless) about addiction or euthanasia. Ethics committees can help health professionals grapple with their concerns and questions.
Second, ethics committees can be proactive. The very fact that a dying patient is experiencing significant pain may raise ethical issues. Ethics committees can examine the situation and offer a forum to educate health professionals, family caregivers, and patients.

Third, ethics committees should review each death to determine whether appropriate palliative care and timely referral to hospice services were offered. Such a practice would be an ongoing reminder to health care providers that no patient should die in needless, treatable pain.

CONCLUSION

Pain management is an emerging frontier in medicine and end-of-life care. There is no reason that a person should die in unnecessary pain. Such a death not only affects the dying person; it exacerbates the grief of survivors and creates increased anxiety about their own future deaths. The cycle of suffering extends beyond the patient.

Numerous barriers exist to effective pain management, but there are hopeful signs. Hospice has demonstrated both a technology and a practical approach consistent with its vision that people can live in relative comfort until they die. The hospice approach is spreading to other health care facilities, such as hospitals and nursing homes. That is the good news. The hope is that more and more people will benefit.

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Dr. Doka was elected president of the Association for Death Education and Counseling in 1993. In 1995, he was elected to the board of directors of the International Work Group on Dying, Death and Bereavement; he chaired the work group from 1997 through 1999. In 1994, he received the award for Outstanding Contributions in the Field of Death Education from the Association for Death Education and Counseling. Dr. Doka is an ordained Lutheran minister.
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