Pain: Impediments and Suggestions for Solutions

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Pain is a common and devastating symptom of cancer that can be effectively controlled with currently available pharmacological and non-pharmacological therapies. Unfortunately, there are reports that half of patients with cancer have inadequate relief of their pain with devastating effects on their quality of life and functional status. Systematic efforts to understand and eliminate the barriers to effective pain control are essential if we are to make pain assessment and management an integral part of cancer care. Documented impediments are related to health care professionals; patients, families, and the public; and the health care, reimbursement, and drug regulatory systems. A research agenda that focuses on closing the gap between current knowledge and practice is essential to assuring that people with cancer are no longer subjected to the agony of unrelieved pain. [J Natl Cancer Inst Monogr 2004;32:124–6]

Barriers to Effective Pain Control

The reasons for undertreatment have been well documented: Impediments related to health care professionals; patients, families, and the public; and the health care, reimbursement, and drug-regulatory systems have been identified (1,9,10). If we are to integrate pain assessment and management into cancer care, there must be systematic efforts to understand and eliminate these barriers to the effective management of pain.

Health Care Professionals

Physicians, nurses, and pharmacists may lack basic knowledge of pain control because pain assessment and management have not been part of professional curricula or residency training programs (9–13). As a result, these professionals may not view pain as a priority in patient care; furthermore, there may be no incentives to change practice. Health care professionals often fear opioid side effects and are confused about the meaning and incidence of tolerance and addiction (11–14). A confounding factor is physician fear of regulatory scrutiny. A 1993 report presented data from a survey of physicians in the Eastern Cooperative Oncology Group. Although 76% rated poor pain assessment as the most important barrier to adequate treatment, 61% said physician reluctance to prescribe opioids was an important factor (11). In 1997, the New York State Public Health Council established an ad hoc Committee on Pain Management to identify the barriers to effective pain management in the state and ways to overcome these impediments. The committee, working in conjunction with the state medical society, surveyed 6000 physicians to assess their fears about possible disciplinary or administrative actions resulting from the use of opioids. A majority of these physicians indicated that they were very concerned about regulatory investigation (15). Unfortunately, patients are often trapped within the skill set and—maybe even more important—the mindset of providers.

Patients and Families

“The effective management of cancer pain is hampered not only by the erroneous beliefs and practices of health care providers, but by the very same problems in patients and their caregivers” [(9), p. 364]. Sandra Ward and her colleagues identified a number of issues that form the focus of patient concerns: the belief that pain is inevitable with cancer, the belief that reporting pain will distract the physician from treating or curing the cancer, the belief that tolerance rapidly develops, the belief that if they are bothering their doctor they are not “good” patients, and the belief that people inevitably become addicted to “strong” pain medicines (16). Very importantly, high levels of patient concerns were correlated with higher levels of pain. Older, less-educated, lower-income patients were more likely to have concerns. More recently, Christine Miaskowski and her colleagues identified lack of adherence to analgesic regimens as a significant barrier to effective cancer pain management in outpatients with bone metastases (17).
Fear of tolerance and addiction, inadequate side effect management, and confusion about the dosage regimen may all contribute to patients’ failure to take their medicines as prescribed. Although half of the terminally ill patients surveyed by Weiss et al. (4) experienced moderate to severe pain, only 30% of them wanted additional pain treatment because of an “aversion to the side effects of opioid analgesia such as constipation and confusion” (4, p. 1314). Weiss et al. also found that “black patients were more likely to . . . refuse additional medication because of fear of addiction than other populations” (4, p. 1311). One-fourth of the caregivers of patients admitted to three Chicago-land hospice agencies were concerned about addiction, tolerance, and side effects caused by medications (18). These individuals were family members, hired caregivers in the home, or staff nurses in skilled care facilities.

**Health Care System**

Further compounding the problem is the fact that pain has had a low priority in the nation’s complex health care system, the focus of which has been on disease management, with inadequate recognition of the critical importance of effective pain management to quality patient care (19). Recognition of this barrier led to the development of pain assessment and management standards by the Joint Commission on Accreditation of Healthcare Organizations (20). There is little question that the standards have increased the visibility and accountability for pain management in settings across the United States. Accredited facilities can no longer ignore pain and have increased pain assessment practices. Although the standards have the potential to change the culture of pain management in the United States, there are no data to tell us whether they have improved pain management practices in accredited facilities (21).

**Reimbursement System**

Adding additional complexity to the problems posed by undertreatment of pain is our unique system of reimbursing the cost of health care. More than 40 million Americans have no insurance to cover the cost of health care (22), and some insurance programs do not cover the cost of prescription drugs. The Medicare Hospice benefit that provides drug coverage for those enrolled in Hospice has been in place since 1985. Until very recently, until the passage of the Medicare Prescription Drug Improvement and Modernization Act of 2003, Medicare did not pay for analgesics for outpatients, forcing many to forgo or limit essential pharmacotherapy. The new law will “certainly help many beneficiaries pay for their prescription drugs, but the process of securing coverage, gaps and all, will pose new challenges for the elderly” (23, p. 832). Ironically, reimbursement policies may favor high-tech interventions such as pumps, blocks, and epidural administration, while not covering oral medications. What is particularly frustrating to most physicians committed to managing pain effectively is that the doctors are not reimbursed adequately for their time.

**Laws and Regulations**

There is evidence that laws and regulations designed to reduce the diversion and abuse of opioid analgesics have had a significant effect on the management of cancer pain (24). The Pain and Policy Studies Group at the University of Wisconsin has systematically identified federal and state legal and regulatory barriers to effective pain control (25). Although opioids are the drugs of choice for the management of the moderate to severe pain associated with cancer, the fears of regulatory scrutiny cited above contribute to the underuse of these drugs (11,15). Those fears are amplified by physicians’ lack of knowledge of basic opioid pharmacology, misunderstanding of the risks of tolerance and addiction, and the belief that aggressive use of these drugs may shorten life (26).

**The Challenges of Special Populations**

“About 77% of all cancers are diagnosed at ages 55 and older” (27, p. 1). Elderly people face many challenges, including limited financial resources, multiple medical problems, decreased family support, and restricted access to health care (28). Pain management is a particular challenge in the cognitively impaired (28); furthermore, clinicians may be unfamiliar with the basics of the pharmacologic management of pain in the elderly. Pain management in minority populations also presents special challenges. “Overall, African Americans are more likely to develop and die from cancer than persons of any other racial and ethnic group” (27, p. 29). Race and ethnicity are important factors that affect care in seriously ill patients (29–31). The increasing ethnic and cultural diversity of this nation demands there be greater priority placed on providing effective pain control in minority populations.

**Directions for Future Research**

**Gaps in Clinical Knowledge**

Despite the advances that have been made in the science and medicine of pain, there are still many knowledge gaps that lead to treatment uncertainties: Which drugs should be used for which pain types and in what sequence? What are the most appropriate routes of administration? Does the effectiveness of drug therapy diminish over time? Will pain medicines interfere with the efficacy of chemotherapy? And, perhaps the most critical question of all, What is a clinically meaningful reduction in pain (32)? In addition, there is a need to develop and test models for increasing the use of nonpharmacologic methods of pain control, for encouraging the rational use of multiple modes of therapy, and for determining effective methods for reducing the frequency and intensity of drug side effects. This litany of issues clearly points to the need for a dedicated clinical trials network and increased federal funding for studies to fill these knowledge gaps. There is a need to develop and determine the validity and reliability of tools for assessing pain in the cognitively impaired and in people of diverse racial and ethnic backgrounds.

It is tragic that there is now no reliable tool for assessing pain in Native Americans. Number scales and scales with colors are problematic. A study of the Ojibwe of Minnesota showed that four tribal communities perceived pain and pain relief differently from one another (33).

**The Need to Change Attitudes and Behaviors**

Even if there were no critical knowledge gaps, there would still be a problem. There is a desperate need for the support of research that will identify the most appropriate ways to change
attitudes and clinical behaviors. There is a need to develop effective strategies for translating knowledge into clinical practice, but to do that, one needs to understand how to change the behaviors of individuals and systems. There needs to be systematic investigation of strategies for changing clinician behaviors. A great deal is known about what does not work (e.g., traditional continuing education alone does not change clinical practice), and new strategies need to be developed and tested (34).

There is also a need to compare strategies for changing pain management practices in different health care settings: What are the most effective and efficient methods for making pain control an integral part of cancer control in the hospital, in long-term care, or in the home care setting? What methods will be successful regardless of setting? What unique challenges are posed by the different care settings?

Models for increasing patient and family demands for effective pain control, for improving patient adherence to analgesic regimens, for dispelling myths about drug side effects and addiction, and for reaching audiences from diverse racial and ethnic backgrounds need to be developed and tested, and systematic clinical trials to determine the risk of addiction in different patient populations need to be conducted.

Finally, there is a need to develop and evaluate the effectiveness of different strategies for changing clinicians’ fears of regulatory scrutiny as well as regulators’ understanding of the role of opioids in pain management and the facts about addiction, and we must also examine the economic consequences and benefits of effective pain control.

CONCLUSION

Although research must be done to address the knowledge gaps, we can not afford to wait for the results of that research before initiating studies to address barriers to effective management of cancer pain. A large body of knowledge now exists. There is no excuse for allowing another decade to go by without there being systematic attempts to bring change.

REFERENCES


