The introduction of any new analgesic agent or delivery system is often focused on efficacy of the agent or on considerations of use by health care professionals. Introduction of novel pain technologies should also consider the

Introduction

A discussion of managing pain in advanced cancer immediately brings to mind the difficult challenges faced by health care providers in their efforts to control pain using multiple methods. However, a discussion on this topic is incomplete without recognition of those most affected by advanced cancer pain, ie, the patients and their family caregivers at home. Advances in pain management, including use of technologies like neuraxial infusion, are important contributions to what has been recognized as a social mandate for improved pain relief. The introduction or dissemination of such advances in pain relief will only be successful if the factors influencing patients and family caregivers in their 24-hour-a-day task of pain management are included.

The shift toward managed care over the past decade and other changes in health care delivery have resulted in a shift in the burden of chronic illness care to patients and family caregivers. These changes have made the home environment the primary setting of cancer care and often reluctant family members responsible for complex care needs. One area of cancer patient care causing great concern to family members is the comfort of their loved ones. This concern was expressed recently by the spouse of a patient being discharged home for terminal care. Crying, she said, “I see him comfortable and relaxed here, and I know that he is going to be sent home because the nurse was making the arrangements. She asked me why I was crying and I said, I’m scared. I’m not afraid of the end, of him dying. I guess I’m tired, and I realize the amount of care he’s going to need at home.”

The impact of pain has been described in terms of its effect on overall quality of life. The quality of life model depicted in Figure 1 evolved over the past 15 years of research at the City of Hope National Medical Center. It describes pain not as a single symptom, but rather captures its influence on overall quality of life.[1-5] Pain profoundly influences physical, psychological, social, and spiritual well being. Cancer pain has been well documented as having a profound influence on the quality of life of both the patient experiencing it as well as the family caregivers who observe it and assume responsibility for controlling it.[3-5]

The understanding of pain in advanced disease has evolved largely as a result of the influence of hospice care. As a primarily home-based service, researchers in hospice have described issues in managing pain at home and brought recognition to the role of family caregivers in pain management. Lobchuk et al[6] and Miaskowski et al[7] have conducted studies of the knowledge of and beliefs about pain in cancer patients and their family members. These studies demonstrated that patients and families have similar knowledge about pain but that family caregivers tend to have greater emotional distress associated with managing pain in their loved ones. Researchers have explored the involvement of patients and family caregivers in outpatient and home care settings in recent literature with very consistent findings. Watt-Watson and Graydon[8] studied the experience of patients with head and neck cancer, focusing on the continuity in pain management from postsurgery to discharge home. Ward and colleagues[9] compared 35 patient and family caregiver dyads who were seen in the inpatient hospice setting. These studies and other literature have documented that family caregivers assume primary responsibility for pain relief despite very limited support and a limited understanding of pain management. The role of family caregivers becomes even more intense with advanced disease.[10-13]
Thus, recognition of the changes in health care delivery in addition to the findings of recent studies clearly document the importance of recognizing issues in pain management at home. Any advance in analgesia or pain technologies must consider the home environment as the ultimate site of the pain experience and its treatment, and must incorporate patients and family caregivers as those who will provide for ongoing decisions and care. New pain technologies often evolve from well-controlled studies conducted in inpatient settings, and successful translation of these treatments to routine care requires an evaluation of the home environment with support provided to patients and families as they assume responsibility for care.

**Knowledge and Beliefs About Pain**

Optimum use of any pain treatment requires that patients and caregivers have adequate knowledge of basic pain principles and that they overcome misconceptions or inappropriate beliefs. Studies have acknowledged that patients and family caregivers often have inappropriate understanding and unrealistic beliefs about therapies for pain such as fear of addiction and fear of respiratory depression, and may tend to use small doses of analgesics or weaker drugs in order to save stronger medications or larger doses for later use if pain progresses.

Studies have documented that pain education must be extended to family caregivers so as to prepare them for the decision-making involved in chronic pain management, including determining the (1) choice of medication, (2) correct doses, and (3) frequency with which analgesics are given. An example of the importance of patient and family knowledge of pain and beliefs about successful use of pain technology has been observed with the use of patient-controlled analgesia at home. Home care nurses have observed instances where patient-controlled analgesia pumps have been implemented at home with the expectation by health care providers that pain management would improve.[14] However, these patients are frequently found not only to have continued uncontrolled pain, but also heightened anxiety. The burden for family caregivers also increases because the technology was implemented without appropriate patient and family educational support.

The use of a patient-controlled analgesia pump must be accompanied by an explanation of basic pain principles such as routine dosing, management of breakthrough pain, and balancing pain relief with control of other side effects. Pain management principles that seem basic to health care providers are monumental tasks for patients and families who often have no prior understanding of these concepts.

Some of the common concerns of cancer patients and family caregivers based on previous studies at the City of Hope are summarized in Table 1. [5,15,16] These concerns must be addressed to ensure successful implementation of any pain treatment at home.

**Pain Education Programs**

Recognition of the importance of overcoming misconceptions as well as providing basic pain management knowledge has led to the creation of pain education programs for patients. One such program, developed and tested by City of Hope investigators from 1989 to the present, involves three components with focus on pain assessment, pharmacologic interventions, and nondrug interventions. The structured teaching of this program, which was evaluated in 81 elderly cancer patients and their family caregivers at home, positively influenced knowledge and beliefs about pain as well as their use of pain medications and nondrug methods for managing pain.[5,15] From 1994 to 1998, the researchers extended their work to include translating the pain education program for use by home care nurses. Findings of this recently completed research have documented that the pain education program can be implemented by clinicians in home care.[17] These studies have also documented the importance of adequate preparation of home care providers in pain management so that they can educate the patient.

In our research, we found that providing families with pain education can move them from a sense of helplessness to a state of helpfulness. The sense of helplessness and frustration was recently described by a husband who was caring for his wife with advanced cancer. He said,

> When she has pain that I can’t control, I feel that I should be able to give her something to stop it. And when that happens, I just feel disabled. I feel like I can’t help her, and that I can’t do what I’m supposed to do. I’m used to fixing things. And when I can’t fix her pain, I feel very, very disabled.

The content of the structured pain education program is summarized in Table 2. One of the findings
of the previously described studies has been that there are unique issues in advanced disease and that patients and family caregivers require additional knowledge and support to sustain pain relief as the disease progresses.

**Cost Considerations**

A third important concern in any advancement in pain relief is cost. Cost considerations must include not only the cost to the health care system or third-party reimbursers, but also the cost to patients and family caregivers. The cancer pain guideline committee of the Agency for Health Care Policy and Research (AHCPR) explored costs associated with pain management. The framework for cost analysis developed by the AHCPR committee is included in Table 3. As the table indicates, there are, in fact, many possible costs associated with pain management beyond simply the cost of medications including oral medications, parenteral or spinal analgesics, surgical or anesthetic procedures, and radiation. However, other costs such as personnel required to implement pain technology must be considered, as should the potential cost savings across various settings.[18]

Consideration of the costs frequently assumed by patients and family caregivers that are not likely to be reimbursed by any third-party source is paramount. A summary of some of the costs incurred by patients and families in pain management at home is shown in Table 4. This list is derived from work originated by Given and colleagues [19] in evaluating general cancer care costs. The City of Hope investigators adapted the cost analysis conducted by Given and colleagues to evaluate costs specific to pain management during the home care study conducted from 1994 to 1998. The presence of unrelieved pain in the patient may require the constant presence of the family caregivers to the extent that they have to give up their employment.

Changes in health care financing have often resulted in patients assuming a larger copayment with managed care plans often eliminating reimbursement for certain services, thus causing an even greater copayment. Many costs are not covered at all and must be assumed completely by patients. The costs identified in Table 4 may reflect those associated with general care, but many may be directly related to pain management.

Pharmacoeconomic outcomes need to be considered when determining the best pain intervention for the patient in pain. These and other outcomes to consider are depicted in Figure 2.

**Ethical Dilemmas in Managing Pain at Home**

Managing pain in advanced disease becomes an intense 24-hour a day responsibility for family caregivers. Numerous studies have documented that family caregivers require not only information, but also emotional support to assume this responsibility.[21-29] Family caregivers have reported struggling with ethical decisions about pain relief and the desire to provide optimum comfort to the patient while avoiding harm.

The introduction of any invasive procedure in the home environment has the potential of intensifying family members’ concerns. Again, the instance of the simple use of patient-controlled analgesia provides experience with this concern. Home care or hospice providers have frequently observed patients in severe pain from advanced disease despite the availability of high doses of strong opioids in the home. When questioned, family caregivers report reluctance to increase doses or to administer bolus doses because of the intense burden of such decisions or the hesitancy to be aggressive in relieving pain in fear of causing harm to the patient. Family caregivers have also been found to be particularly hesitant to administer analgesics when patients become less responsive or there is a decrease in their respiratory rate or blood pressure.

These findings remind us of the importance of reinforcing previous pain education as the patient’s status becomes more advanced and of addressing new concerns associated with terminal illness. In previous studies at the City of Hope, investigators found that pain was the metaphor for death for family members who often see increased pain as a sign of imminent death. Families often have a tendency to deny the reality of increased pain in order to avoid the reality that the patient may soon die.

**Summary**

Advances in pain management, particularly those useful in end-of-life disease, are welcome. However, successful implementation of any pain technology will occur as research from well-designed clinical trials is translated into actual use by patients and family caregivers at home. Recognition that pain management rests in the hands of patients and their family caregivers and
that such care is contingent upon adequate knowledge and beliefs is the first step toward successful use of these treatments. Health policy and reimbursement considerations are essential amidst an increasingly burdened health care system in which all costs must be considered and benefit must be demonstrated to justify the increased costs of health care.

Finally, the effective use of any analgesic must recognize the unique aspects of pain management as a component of cancer care. Managing pain is unlike any other aspect of cancer care as it inherently brings to play issues of ultimate comfort, quality of life, and the ever-present possibility of death. Decision-making and the ultimate burden of care for family caregivers are very real issues and integral to successful use of pain relief modalities. Each of these concerns and burdens, however, are also balanced by a recognition that effective pain relief for patients at home, supported by health care providers, can result in improved comfort and quality of life for both the patient and the family caregiver.

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