The Role of Ethics Committees in Responding To the Moral Outrage of Unrelieved Pain

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In recent years professional organizations, international societies, and governmental agencies have recognized the problem of unrelieved pain. Failure to provide adequate pain relief is both a clinical problem in health care, but also a moral outrage as patients endure needless suffering. Previous literature has focused primarily on the role of clinicians to respond to this problem. Ethics committees also play a vital role in insuring institutional commitment to pain management. Ten strategies for involvement of ethics committees in improved pain management are presented.

n recent years, professional societies and journals have paid significant attention to the __problem of unrelieved pain. There is strong consensus that pain associated with both acute and chronic illness has been poorly managed. Literature from professional organizations, pain researchers and clinicians, federal guideline panels, and others have agreed that unrelieved pain is a norm, with estimates that approximately fifty percent of patients after surgery and sixty to eighty percent of those with chronic or terminal illness experience unrelieved pain (AHCPR 1992; AHCPR 1994). Pain is known to impact all dimensions of quality of life (QOL) including physical, psychological, social, and spiritual well being (Figure 1) (Ferrell 1995). Pain impacts not only the patient, but also those individuals who observe it and who often share the intense suffering associated with failure to respond to it.

Recommendations for improved pain management from national guidelines and standards address the role of physicians, nurses, and other clinicians who provide direct care to patients in pain. While these clinicians are most intimately involved with the management of pain, ethics committees also play a vital role as agents of change, advocacy, and accountability in this emerging problem.

Recent events have contributed greatly to the current discussion of a national mandate to

improve pain management. The public debate over assisted suicide and euthanasia, for example, has been fueled by the demand for more humane care for the terminally ill. Public perception that death must be accompanied by unrelieved pain has resulted in the public demand for alternatives, and this, unfortunately, has translated to a demand for assisted suicide or euthanasia. In response, leaders in hospice and pain management have asserted strongly that the United States does not need assisted death, but rather needs a national effort to provide optimum palliative care (Coyle 1995; Ferrell 1997).

In concert with the need for improved clinical care for those individuals in pain, there is an unrecognized opportunity for ethics committees to provide the leadership that can result in institutional change, guaranteeing an improved standard of care for all patients in pain. The following strategies summarize essential opportunities for ethics committees to respond to what has been deemed a moral outrage of unnecessary pain and suffering. These strategies come from the author's ten year's of work in implementing institutional efforts toward improved pain management.

Increasing Visibility of the Problem of Unrelieved Pain

Despite the fact that pain is a common problem, it remains largely an invisible one. Unlike other medical emergencies such as hypertensive crisis, hemorrhage, or high fever, there is little visibility for the problem of unrelieved pain. Previous literature suggests that most health care providers believe that their patients are comfortable and that there is often an inherent denial of the patient's pain within the health care provider/patient relationship. Ethics committees can be centrally involved in promoting increased visibility of the problem of unrelieved pain through activities such as implementation of standardized pain as-

sessment and by promoting policies and procedures that insure pain is assessed, reported, and documented (AHCPR 1994; APS 1991). Standardized pain assessment scales, which ask the patient to rate the intensity of their pain, have been published widely. Making the problem of pain visible is a necessary first step to other strategies. Many institutions have witnessed the enormous benefit of making pain a visible and unavoidable clinical problem.

Quantify the Current Status of Pain Management

Historically, ethics committees have played a role in being the "facts finders" in order to document violations of human rights and shortcomings in systems of care. Numerous instruments exist that can be used by ethics committees in quantify-

ing the current status of pain management, such as use of patient interview tools, chart audits, and follow-up surveys of patients after discharge. Ethics committees have an opportunity to make the current status of pain management visible and to document specific areas that need improvement. For example, such audits commonly result in strong evidence pointing to specific problem areas, such as a lack of analgesia prior to painful procedures; inadequacies in pain relief for the most vulnerable patients, such as infants or frail elderly; failure to provide the most current analgesics and therapies; and a lack of access to non-pharmacologic pain management strategies. Through these activities, ethics committees can

Table I

Opportunities for Ethics Committees to Improve Pain Management

- Increase visibility of the problem of unrelieved pain.
- Quantify the current status of pain management.
- Promote the need for, and acceptance of, an acceptable standard of care.
- Model the concept of an interdisciplinary approach to the problem of pain.
- Advance professional knowledge, beliefs and competence in pain management.
- Insure patient education regarding pain to enhance autonomy and to promote consumer expectations for pain relief.
- Lead institutional efforts to recognize and eliminate regulatory barriers to pain relief.
- Advocate for elimination of unethical practices related to patients in pain.
- Serve as a moral voice for vulnerable populations.
- Hold institutions accountable for the level of pain relief and recognize failure to relieve pain as a moral outrage.

serve as catalysts, providing necessary data to initiate efforts by other institutional committees to address the clinical problems (Ferrell, Whedon, and Rollins 1995; Ferrell 1994; Ward and Gordon 1994).

Promote the Need For and Acceptance Of an Acceptable Standard of Care

Pain management has been criticized quently in clinical settings because of the inconsistency in care between patients and across clinical areas. It is common for patients on a given surgical unit, having experienced similar surgical procedures, to have widely varying degrees of pain relief depending upon the surgeon or nurse caring for the patient. Despite advances in pain management and

awareness of the best practices for specific types of pain, pain management remains largely a function of the individual physician with no accountability for that practitioner to aspire to a higher standard of care. It is common to observe clinical

practice that is in wide variation to what is known to be practice based on the best scientific evidence. For example, although Demerol (Meperidine) is documented as a poor choice of an analgesic, it is still commonly used for pain. Other practices are also common, such as the administration of analgesics only on a PRN (as needed) basis, rather than on an around-the-clock schedule for optimum comfort. As ethics committees have demonstrated in other clinical areas, promoting more consistent care and standards of acceptable practice is often the key to insuring a change for all patients in an institution.

Model the Concept of an Interdisciplinary Approach to the Problem of Pain

Pain, perhaps more so than any other experience of illness, is a multidimensional one (Ferrell, Grant, Padilla, Vemuri, and Rhiner 1991). It profoundly effects the physical, psychological, social, and spiritual dimensions of life. The relief of pain demands an interdisciplinary approach to treat not only the physiologic cause of pain, such as a fractured bone or pressured nerve, but also to address other human dimensions influencing pain. Ethics committees often embody the premise of interdisciplinary care; their involvement in the problem of pain can serve as a model for attending to the multiple dimensions of optimum pain management.

Advance Professional Knowledge, Beliefs, And Competence in Pain Management

It is a basic fact of care that patients cannot receive services that are unknown to the health care providers who care for them. In other words, professionals cannot practice what they do not know. Unfortunately, previous literature has documented strongly the fact that most health care providers do not have a basic understanding of current principles of pain management. Numerous studies have documented the failure of medical, nursing, and other professional schools to teach basic pain principles and indicate that they are even less likely to address new advances in analgesia (McCaffery and Ferrell 1994; Ferrell, Grant, Ritchey, Ropchan, and Rivera 1993). Just as we would not expect patients to receive opti-

mum treatment of infections or cardiac problems if knowledge in these areas remained unknown, we cannot expect health care providers to improve pain management until they are more knowledgeable and competent in the practice of pain management.

Ethics committees have an opportunity to advocate for basic standards for professional knowledge through continuing medical educational conferences, new staff orientation, new student orientation, and establishing basic clinical competence. As institutions move toward establishing clinical competency as a measure of quality, ethics committees should advocate to insure basic levels of pain knowledge for professionals within the institution.

Ensure Patient Education Regarding Pain To Enhance Autonomy and to Promote Consumer Expectation for Pain Relief

Professionals who have been involved in advocating for improved pain management know that often they are advocating for improved pain management when, in fact, patients and family caregivers have low expectations of pain relief and minimal understanding of the problem of pain. Patient and public misconceptions about addiction, tolerance, and safety concerns such as respiratory depression greatly influence care provided (Ferrell, Rhiner, and Ferrell 1993).

Materials are available at minimal cost for use in patient education for pain management. The Mayday Pain Resource Center (MPRC) established at the City of Hope National Medical Center identifies existing pain materials including patient education materials (Figure 2). Many institutions have incorporated patient education strategies such as the use of video or audio taped instruction or use of closed circuit television. The AHCPR (Agency for Health Care Policy and Research) Cancer Pain Guidelines (1994) identify patient barriers to pain management as one of three major areas targeted for improvement. Patient education in pain must incorporate information and also overcome myths and misconceptions surrounding pain and the use of analgesics.

Figure I

Pain Impacts the Dimensions of Quality of Life

Physical Well-Being & Symptoms

Functional Ability
Strength / Fatigue
Sleep andRest
Nausea
Appetite
Constipation

Psychological Well-Being

Anxiety
Depression
Enjoyment / Leisure
Pain Distress
Happiness
Fear
Cognition / Attention



Social Well-Being

Caregiver Burden
Roles and Relationships
Affection / Sexual Function
Appearance

Spiritual Well-Being

Suffering
Meaning of Pain
Religiosity
Transcendence

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Lead Institutional Efforts to Recognize And Eliminate Regulatory and Legal Barriers to Pain Relief

Achieving effective pain management requires a merging of ethical, moral, and legal efforts aimed at diminishing pain and suffering. Unfortunately, many legal and regulatory barriers exist to adequate pain control. As mentioned above, the AHCPR Pain Guidelines (1994) identified three chief barriers to pain management — professional barriers, patient barriers, and regulatory barriers. Clinical experience and research has documented that the third category, regulatory barriers, is a significant one that must be overcome.

Most of these barriers are related to laws and professional regulations that limit the prescribing of controlled substances, such as opioids, for pain relief. In an attempt to decrease substance abuse and drug diversion, the government has enacted laws related to the prescribing of analgesics and has instituted systems requiring multiple prescriptions, limits on amounts of medications to be prescribed, and many other restrictions (Joranson 1993; Fife, Irick, and Painter 1993; Hill 1993).

While few professionals are scrutinized by drug enforcement agencies, the perception of possible review or loss of license is a major impediment to prescribing pain medication adequately. Ethics committees can evaluate the impact of such barriers on prescribing medications within their institutions. Some clinical settings have mandated that all physicians have prescription privileges necessary to prescribe the medications needed by patients with pain. Ethics committees also can be an active voice to convey the clinical needs for improved pain management to regulatory and legal bodies.

Advocate for Elimination of Unethical Practices Related to Patients in Pain

Basic principles about ethics, such as patient autonomy, nonmaleficence, veracity, and beneficence, are applicable to the clinical issues of pain management. Ethics committees can advocate for establishing policies and standards of care that address ethical issues in pain management, such

as opposing the use of placebos for patients in pain. In 1996, the Oncology Nursing Society developed a policy statement against the use of placebos, which has been endorsed by more than twenty-five other organizations (McCaffery, Ferrell, and Turner 1996). Other dilemmas addressed by ethics committees have included use of conscious sedation for terminal pain, informed consent related to pain research, and other clinical issues.

Serve as Moral Voice for Vulnerable Populations

Much of the focus on improving pain management, such as advocating for greater pain education, will reach the most educated, articulate of patients. It is essential to recognize that the most important focus of improved pain management should be vulnerable patient groups. Individuals with a history of substance abuse, those with nontraditional lifestyles, AIDS patients, non-English speaking patients, and those without family advocates are at high risk of receiving inadequate pain relief. Ethics committees can target efforts to insure pain relief for these groups.

Hold Institutions Accountable for the Level of Pain Relief and Recognize Failure To Relieve Pain as a Moral Outrage

The movement toward improved pain management began in the 1970s as a quiet, isolated voice primarily confined to the hospice community. Many events have led to the current public and professional attention to pain as an emergent health problem (WHO 1990). The movement to improve pain relief must now be a loud and unified voice and must extend across clinical settings and disciplines.

These strategies are intended to initiate activity by ethics committees. In order for such activity to have lasting impact on pain management, ethics committees need to share with others their experiences of both successes and barriers in changing the practice of pain management. Ethics committees, and most importantly the dedicated professionals who are members of these groups, are a vital force in diminishing unnecessary pain and suffering.

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Figure 2

Mayday Resource Center

Through a grant from the Mayday Fund, researchers at the City of Hope National Medical Center established the Mayday Pain Resource Center (MPRC) in January, 1995. The purpose of the MPRC is to serve as a clearinghouse to disseminate information and resources that will enable other individuals and institutions to improve the quality of pain management. The MPRC is a central source for collecting a variety of materials related to pain including pain assessment tools, patient education materials, quality assurance materials related to pain, research instruments used in pain research and other resources. The MPRC now includes more than 250 materials available for distribution. Individuals and organizations are asked to contribute any materials related to pain management that will benefit others. You are invited to contribute any materials related to pain that may be useful to others. To obtain an index of materials, please contact:

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