Ethics and Pain Management:
Respecting Patient Wishes

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Abstract
The fear of pain is common among cancer patients. The management of cancer pain can raise troubling ethical issues for medicine and society. Medical caregivers have an ethical duty to provide therapy that benefits patients by achieving one or more goals of medicine at all points. Pain and symptom relief may be the only achievable goal when curative therapy has failed. Relief of pain can restore decision-making capacity and enhance the patient’s right to self-determination. The underpinning ethical principles and extensions of these principles in the medical context of pain control with varying medical goals in cancer care, including dying patients, is explored. J Pain Symptom Manage 1994;9:160-165.

Key Words
Ethics, cancer pain, terminal care, autonomy

Introduction
The management of cancer pain raises troubling ethical issues for patients, families, health-care providers, and society. These issues revolve around moral rights and responsibilities, not only of patients, but also the broader group of individual caregivers, government, medical insurers, medical schools, licensing boards, and administrators involved in health care. Many of these issues have been raised in recently developed cancer pain guidelines: inadequacy of pain relief, adequate patient participation, respect for patient context, and issues of access to and coverage for adequate pain care. While the clinical barriers are well defined, lack of appreciation for the ethical dimensions of pain management can create its own barrier. This report is intended to expand the discussion of those issues by emphasizing three basic ethical elements:

1. The dying cancer patient should never be allowed to live out his or her life with unrelieved pain because of fear of side effects.
2. Respecting patient wishes—autonomy—must have a high ethical priority in cancer pain management.
3. The role of the health-care provider must be one of advocacy for both individual patients and those who will need care in the future.

Duty to Benefit and Obligation to Treat Pain
The goals of medicine listed by Jonsen and colleagues1 include relief of symptoms, pain,
and suffering; improvement of functional status or maintenance of compromised status; education and counseling of patients regarding their condition and its prognosis; cure of disease; preventing untimely death; and promotion of health and prevention of disease. At any time during the management of a patient with cancer, the indications for treatment must benefit the patient by achieving one or more of the goals of medicine. The clear limit to benefit is harm. Pain control relieves symptoms and may restore function. Other modalities of cancer therapy over the course of a patient's disease process may have a smaller margin between benefit and harm and may indeed become futile—that is, they provide no, or very limited, benefits and meet no goal of medicine. Physicians are ethically not obligated to offer therapy that will not benefit patients. In a terminal cancer patient, when the only therapies of benefit are symptom palliation and augmentation of function, pain control assumes an even greater ethical importance. Relieving pain and suffering becomes the major medical goal.

In this context, the side effects of high opioid doses can create fears in the treating medical personnel about harming or even killing patients when increasing doses to alleviate pain. The duty to benefit through relief of pain is by itself adequate to support the use of increasing doses to alleviate pain, even if there might be life shortening and expected side effects. Those treating the patient clearly intend an adequate dose—and only that—to relieve pain. In doing so, they accept the potential sequelae. This concept has a long history in moral thought—and has been framed as the principle of double effect.

The principle of double effect delineates the clinical situation when an intended treatment may have inextricably linked deleterious side effects. To meet this ethical concept, the intent of treatment must be clearly focused on the good or beneficial (and medically appropriate) outcome. The treatment must be not morally objectionable in and of itself. The administration of medication is always a risk-versus-benefit calculation. When the patient's death is imminent because of progression of primary disease, an increased risk of earlier death counts little against the benefit of pain relief and painless death. Given the fact that most of these patients have been receiving opioid analgesics for a significant period of time, the feared shortening of life with side effects is not likely. The dying cancer patient should never be allowed to live out his/her life with unrelieved pain because of fear of side effects.

The appropriate, aggressive palliative support of a dying patient differs from the concept of physician-assisted death or euthanasia. The idea of unrelieved pain for which assisted death is the only alternative has been debated in many forums, including broad initiatives in Washington and California that incorporate assisted suicide.

The intent of medical intervention in assisted suicide differs markedly from the intent of treatment when death is a secondary accepted risk. In assisted suicide, a morally objectionable means or intent (killing) is the treatment used to achieve a morally permissible end (pain relief). During the discussion over state initiatives, supporters revealed a telling fact: they were attracted to these measures because they feared spending their dying days in uncontrolled pain. Fear of unacceptable pain formed a major component of requests to physicians for assisted death and is so important to patients with cancer that 69% reported they would consider committing suicide if their pain was not adequately treated.

The concern that the stimulus for legalizing assisted death comes from inadequate attention to pain and symptom management is also supported by research showing that 81% of physicians and nurses felt that “the most common form of 'narcotic abuse' in the care of the dying is the undertreatment of pain.” The ethical principle of autonomy encompases the critical importance of patients' rights to self-determination regarding health care. A significant element of the care of cancer patients and their pain management is the high priority given to respecting patients'
wishes from their own context. The kind of pain management and side effects that are acceptable to patients varies directly with their present and future goals, and their unique view of themselves and the world. Caregivers’ assumptions, without corroboration, of patient wishes, values, and educational needs often lead to rejection of helpful therapy or to acceptance of therapy with a heightened sense of loss of control over one’s destiny. This sense of control may already be beleaguered by the diagnosis and therapy of malignancy.

Consider a 75-yr-old patient who is admitted with a large, fungating vulvar mass for which primary chemotherapy and radiation therapy is considered. The patient is ill-kempt, does not meet the staff’s eyes when questioned, and states she just “wants to die.” She has no appetite and has lost 20 pounds over 6 months. She wants pain medicine to “put her to sleep.” She is ambivalent about treatment. While autonomy is a deeply held ethical principle in medical ethics, respecting patient “wishes” involves far more than accepting the face value of a patient’s expression of wishes.

This example illustrates an important element in assessing patient capacity to choose: the authenticity of an expressed wish. The overriding element of untreated depression creates a valid question about the ability of this patient to make choices about her care. The recognition and treatment of depression can be considered as an effort to restore authentic autonomy, allowing the patient the ability to consider carefully, correlate, and communicate his/her wishes and goals. The prevalence of unrecognized depression in patients, particularly those expressing a desire to abandon all therapy and to die, is significant. Severe, unrelieved pain itself should be considered a major impingement on a patient’s ability to make choices regarding care and ethically obligates health-care workers to treat such pain on the basis of restoring autonomy as well as beneficence.

The obligation of health caregivers to accurately identify patient wishes becomes more stringent when patients are unable to speak for themselves. Any surrogate decision maker should decide as the patient himself or herself would have wished, but information about what a patient would have wished may be limited. The passage of the Patient Self-Determination Act (PSDA) is a clear message to health caregivers that the population wants a durable dialogue with caregivers about what medical interventions are useful to them. The PSDA requires hospitals receiving federal funds to ask patients whether they have advance directives and, if advance directives do not exist, information regarding them must be offered.

One of the most clearly delineated of patients’ wishes is adequate attention to pain and symptom management in all phases of care particularly for dying patients. It is reasonable, then, to treat pain in cancer patients who are unable to make choices or who have no surrogate decision makers because not only does it meet a beneficial goal of medicine or restore autonomy, but also is a reasonable assumption about a patient’s wishes for pain management.

Advance directives can afford valuable information when choices must be made for patients with limited or no ability to speak for themselves. These generally include directives to physicians (or “living wills”), which may or may not be in a format acceptable in the particular state. Even if not in a proper format, these documents can give caregivers information about what the patient’s choices might have been. Also, durable powers of attorney for health care can identify a person whom the patient has chosen to make such choices. Both can provide health caregivers with significant information about what a particular patient would have wished in present circumstances.

A number of investigators, including Strull and colleagues, have demonstrated a desire to discuss such issues, including pain management, in approximately 60% of the patient population. Nonetheless, the number of patients actually discussing this with physicians is less than 8%. Clearly, the burden of introducing these issues—the opening of the door—is on physicians’ shoulders.

Information that can be considered by patients, families, and their physicians at a time when impending crisis management is not looming large represents a greater respect for encouraging accurate expression of wishes and values. Whether in the outpatient or inpatient setting, the physician bears a significant moral burden of opening this discussion. These
representations of patient wishes must be carefully evaluated at sequential times, as they must meet the criteria of representing the patient's choices given the current medical circumstances. Establishing early on in cancer therapy the patient's goals relevant to mobility, level of awareness, and side effects of pain management will be very helpful when medical decisions may later need to be made by a surrogate decision maker. This basic discussion may be revisited as intensity of treatment or goals of therapy shift.

No advance directive is valid if the patient still has the capacity to make choices. Even if a patient has an advance directive refusing hydration, invasive procedures, and so on, a medical indication for these interventions requires that the patient with capacity participate in choices—even if the patient is terminal. Assumptions about pain management, nutrition, hydration, and other needs, should never be made on the basis of advance directive documents when continued dialogue with the patient is possible. Furthermore, surrogate decision makers, either as specified by state statutory law or by a durable power of attorney, should not blindly be accepted by caregivers as choosing in the patient's best interest. The patient may have clearly communicated a desire for palliative and maximal pain management that included moderate degrees of sedation. A family member or surrogate may have unfinished business with the patient or become anxious at the thought of losing a loved friend or relative, and demand as the patient's surrogate that therapy be given or a pain-management plan be altered. Although this person's grief must be attended to by the patient's caregivers, the patient's decisions remain the guiding principle. The patient's benefit and wishes regarding care remains the primary obligation of caregivers.

The Obligation to Relieve Suffering: Looking Beyond Pain

Another case may extend this illustration. A 35-year-old has progressive, untreatable cervical cancer. Her goal is to spend time with her children, ages 10 and 12 yr. She has severe pelvic pressure and pain but desires a clear sensorium to interact with her children. Mobility is not as important to her. The information gathered from the patient directs her cancer pain-management alternatives. For the patient's benefit and out of respect for her choices, optimal management of her refractory pain with preservation of cognitive function should be explored through all avenues. This might also include the expert advice of a pain or palliative medicine specialist. Correlating the final plan, particularly when more technologic solutions are required, with insurance coverage options and available care sites further refines the medical decision making. This becomes the best way of framing the medical decisions that affect a patient's quality of life—in the patient's framework of priorities.

There remain significant barriers to cancer patients achieving such quality-of-life goals. Not infrequently, the optimal setting for the care to achieve the patient's goals for quality of remaining time (to see her children, for example) may not be possible given her insurance coverage or available caregivers. Also, the medical-care setting may not recognize the patient's needs. Health caregivers' assessments of the degree of pain suffered or the relevance of symptoms reported have been notoriously biased by sex, socioeconomic status, and ethnicity of the patient. The ability to "predict" what is "satisfactory" for the patient is difficult and an attitude of respecting and seeking the patient's perspective and advocating for that outcome is a basic ethical duty. The ethical responsibility of the health-care system to adequately address pain management will require a response to the greater context of relieving suffering and distress reflected by these issues.

In the Cancer Pain Guidelines, the assumption of adequate insurance coverage to receive optimal pain control underpins the discussion. A related concern expressed in debates over assisted suicide was the fear that lack of access to optimal pain control or a fear of leaving a family destitute in order to achieve optimal pain control would lead to biased pressure for the poor or underinsured to choose assisted suicide as a pain-relief measure. The issue of allocation of resources and the method of just allocation is clearly at the ethical heart of this and other debates surrounding pain relief. A generally supported ethical viewpoint is that
both equal access to medical care and availability of a decent minimum of medical care are reasonable expectations of human beings.\textsuperscript{21,22} Certainly a basic medical goal such as the relief of suffering and pain should hold a high priority in any package of basic medical care determined by insurance and public policy.

The issue of what level of appropriate pain technology, nursing assistance, setting, cost, and adjunctive social support is justified (or just) must be decided for insurance packages. Methods of resource allocation that are used to decide coverage for individuals could be decided by the categories of best medical utility, chance and queuing (first come, first served), or social utility (both the greatest good for the greatest number and social worth). Resource allocation now and in the future mandates involvement of health caregivers in assuring that the best interests of patients are represented for all areas, including pain management.

Presently, allocation follows different forms. Elaborate social tables of values have been drawn—for example, in Oregon\textsuperscript{23,24} to prioritize areas of highest value to the population, and pain control rates high on these lists. The present solution to the allocation of health care is a system of hidden costs and limited access by bias, which is sometimes based upon gender, socioeconomic status, ethnicity, and health-plan vagaries. Such a hidden system offers no opportunity for dialogue about allocation and what system of just allocation should guide us.

Ethically, the role of the health-care provider must be one of advocacy for adequate cancer pain management for both individual patients and those who will need care in the future. That advocacy includes recognizing that allocation and denial of resources is already occurring, identifying this, and promoting long-term and short-term policy debate to formulate social consensus about a “just” system of allocation of care. Such a system will encourage the treatment of pain and the greater dimensions of suffering\textsuperscript{24} for all cancer patients.

These ethical dimensions of pain management for cancer patients must be confronted as diligently as the clinical and pharmacologic dimensions. The imperative to address these issues extends from the bedside to the determination of health care policy. Effective action to respect the basic ethical rights of patients with cancer to adequate pain control affirms the value of life even in the shadow of imminent death.

\textbf{References}


