Emerging Ethical Issues in Palliative Care
[Contempo 1988: Updates Linking Evidence and Experience]

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PALLIATIVE CARE—the comprehensive, coordinated, and concentrated relief of both pain and suffering in terminally ill or incurably ill patients—has always been a moral responsibility of physicians, regardless of specialty. [1-3] For several reasons this moral obligation has today become more important than ever: physicians still provide inadequate pain relief; public opinion is becoming more tolerant of assisted suicide when patients are perceived to be suffering intolerably; while denying a constitutional right to assistance in suicide, the Supreme Court has voiced unequivocal support for adequate pain relief; and palliative medicine has become an area of expertise in its own right. [4-6]

These developments prompt a review of some of the central ethical issues peculiar to palliative care. These issues are pertinent for all physicians caring for patients regardless of the cause of their suffering and whether or not these physicians are specialists in palliative care. [7,8]

Relief of Pain and Suffering

The availability, accessibility, and effectiveness of modern methods of pain control make it morally mandatory for every physician to be knowledgeable in the use of analgesics. [9] Not to relieve pain optimally is tantamount to moral and legal malpractice. Despite this, many physicians still lack the requisite knowledge or use analgesics too parsimoniously. Some fear
addicting the patient; others, the ethical responsibility if death were to occur as a result of respiratory depression.

These fears are not justified factually or ethically. For example, it is known clinically that patients with severe pain receiving large doses of opiates rarely, if ever, suffer respiratory depression or addiction if doses are properly titrated. [10] Even if addiction were to occur in terminally ill patients, it would be a small price to pay for relief of suffering. In nonterminally ill patients with chronic illnesses, a more nuanced approach to pain relief is warranted, however.

From the ethical point of view, doses of analgesics sufficient to relieve pain, which, as an unintended effect, might hasten death, are permissible if the conditions of the "rule of double effect" are observed. [11-13] Although this rule has been challenged, it remains important if used properly. [14] Under this rule, an action having 2 effects, 1 good and 1 bad, is permissible if 5 conditions are fulfilled: (1) the act itself is good or at least morally neutral, eg, giving morphine to relieve pain; (2) only the good effect is intended (relieving pain) and not the bad effect (killing the patient); (3) the good effect is not achieved through the bad effect (pain relief does not depend on hastening death); (4) there is no alternative way to attain the good effect (pain relief); and (5) there is a proportionately grave reason for running the risk, eg, relief of intolerable pain. Clearly, to justify use of this rule, the patient would need to be informed of the risks and give valid consent.

Physicians' fears of legal consequences should also be allayed. In their ruling denying a constitutional right to physician-assisted suicide, the Supreme Court justices strongly affirmed the physician's obligation to provide adequate pain relief even if this might unintentionally accelerate death. [15,16] Though they did not explicitly refer to it, their reasoning was analogous to that used in the rule of double effect. Indeed, so unequivocal was their assertion of the obligation to relieve pain and suffering that it has been interpreted as a putative "constitutional right" to palliative care. [17] Whether this is the case and whether this justifies relaxation of federal regulations regarding the use of narcotics may be problematic. [17] What is clear is that there is ethical and legal sanction for the use of whatever doses of narcotics are necessary so long as death is not directly intended.

If the doses of narcotics necessary to relieve pain are large enough to produce deep sedation, this too would be permissible, if suffering can be relieved in no other way. This is not, as 1 commentator argues, [18] the same as "slow euthanasia" since the intent is not the death of the patient. Deep sedation is intended to relieve pain and suffering, not to cause the patient to refuse food and fluid and thus cause death. To hasten death by terminal sedation would violate the rule of double effect since the good effect—relief of pain—would be achieved by deliberately accelerating death. [18]

**Autonomy and Consent**

As with any program of treatment, consent for palliative care must be obtained from patients with the capacity to make their own decisions; it cannot be assumed. Full disclosure is requisite so that the patient realizes he or she will be cared for by a multidisciplinary team of physician specialists, nurses, social workers, pastoral care counselors, physical therapists, pain specialists, psychologists, and psychiatrists. The psychosocial aspects of suffering in particular require probing the patient's private life, relationships, and religious beliefs. [19] All patients may not wish to undergo this comprehensive inquiry into the causes of their suffering. They may wish only optimum pain relief, and this should be their privilege.

Patients receiving palliative care are especially vulnerable and susceptible to suggestions about unorthodox treatment. Many Americans already choose so-called alternative medicine alongside conventional therapy. They are increasingly drawn to such treatment when conventional curative therapy fails. This is clearly the case with incurably ill patients. If such alternative treatments are not per se harmful, and if they do not compromise the effectiveness of palliative care, there seems to be no ethically compelling reason to deny the patient this privilege. Physicians who consider such treatment "unethical," of course, must be free not to participate. They should explain why they cannot use these methods respectfully and courteously. If agreement cannot be reached, the patient may discharge the physician, or the physician may respectfully withdraw as soon as another physician agrees to undertake care.

Also under the rubric of patient autonomy is the issue of truth telling. Presumably patients are aware of their limited prognosis for life when they enter a palliative care program. Incomplete or selective understanding, denial of the futility of cure or unwillingness to be reminded of their impending deaths may lead patients directly or indirectly to desire less than the whole truth. There are also preferences in certain cultures that may dictate discussions with the family and not with the patient. Autonomy is not the central value for many cultures that it is in Anglo-American ethics. Empathetic accommodation to the patient's and family's mores is preferable to an overzealous insistence on handling all patients in 1 way. On the other hand, deception is not permissible. Direct questions must be answered directly. The decision of how much of the truth to reveal, how detailed, how timed, remains a matter of the highest sensitivity for which no general formula is adequate.

In this respect there is an obligation to use terms like terminally ill with caution. The difficulties in the use of this terminology have recently been reemphasized. However, anticipation of death, even when the short-term prognosis appears good, is essential if decision making is not to occur in the midst of a crisis or sudden decline in the patient's state. Truth telling and short-term prognosis and anticipation of death are closely linked in the clinical care of any patient in whom death is foreseeable but not necessarily imminent.

**Ethics of the Team**

Palliative care is, of necessity, team care since no single profession could possibly meet all the varied needs of terminally ill patients. This fact introduces the special ethical issues associated with collective human activity.

Central is the question of accountability. In 1 view, each team member may be accountable only for his or her specific function on the team. Yet team members cannot avoid responsibility for group decisions and actions in which they participate willingly and cooperatively. Then there is the question of team captaincy—and the extent of authority of the "captain." Ideally, captaincy should be related to the predominance of patient needs and therefore could rotate among team members, or the captain should be the convener, but not the ultimate authority. Physicians cannot assume authority over others in ethical matters. Each team member is an accountable moral agent. Granting this, there is still the inescapable fact that the physician who writes an order cannot escape moral complicity by ascribing his or her action to "team will." When team members are at odds, an ethics committee may be useful in arriving at a morally defensible course of action. If this is not possible, ultimately the patient (or patient surrogate) and physician will have to decide whether to continue their relationship.

Accountability can be lost sight of in the vagaries of team dynamics. Some team members
may avoid dissent to avoid offending colleagues; others may become infatuated with "team wisdom" to the detriment of the patient's wisdom about his or her own illness; others may be more concerned about the "anguish" of the caregiver than the anguish of the patient. A team can develop a self-righteous opinion of the good it is doing and thus give its decisions self-justification, thereby infantilizing the patient. Palliative care teams must recognize the centrality of the patient while retaining their own personal and professional integrity.

Avoiding Ideology

Finally, palliative care is so morally admirable in its aims that its methodology can become an ideology-the only "right and true" way to die. This medicalizes and professionalizes a process that depends as much on personal commitment to a friendly interest in the patient as it does on technical expertise. Many of the skills required for compassionate terminal care are less technical than personal. Family physicians, friends, and families may be more responsive to these dimensions of care than some palliative care specialists. If palliative care becomes an ideology, it can discourage and displace the loving efforts of family and friends, submerge the patient in "the system," and frustrate the ends and purposes of palliation itself.

Oncologists have a responsibility to recognize when the benefits of treatment with chemotherapy or radiation have reached their limit so as not to delay comfort and palliative care unnecessarily. In this respect, it would be beneficial if oncologists and others whose specialties involve the care of dying or chronically suffering patients were to spend time during their training in hospice or palliative care.

Oncologists understandably are oriented to aggressive therapy, and this is often to the patient's benefit-but not always. Primary care physicians for their part are more inclined to palliation and perhaps move in that direction too soon. Their education should include familiarity with contemporary methods of cancer therapy.

From the patient's point of view, both oncologists and generalists must recognize their own biases in treating fatally ill patients. They must communicate better and work cooperatively. Palliative care is fundamentally good comprehensive care, and it should be part of the care of all patients, whether they are receiving vigorous anticancer treatment or hospice care. Generalists, oncologists, and other specialists are obligated to coordinate their patients' care because the good of the patient demands it.

Palliation must be subservient to the special needs of incurably ill patients without an overcommitment to rigid programs that too easily take on a life of their own. Even so meritorious an initiative as comprehensive palliation of pain and suffering must be practiced within clearly established ethical constraints. Compassion, like any human affect, may be distorted and become an instrument of professional power rather than of patient welfare.

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REFERENCES


University Press; 1972:2:299. [Context Link]


4. Canadian Palliative Care Association. Palliative Care: Toward a Consensus on Standardized Principles of Practice. Ottawa: Canadian Palliative Care Association; 1995. [Context Link]


6. Woodruff R. Palliative Medicine: Symptomatic and Supportive Care for Patients With Advanced Cancer. Melbourne, Australia: Asporula; 1993. [Context Link]


17. Burt RA. The Supreme Court speaks: not assisted suicide but a constitutional right to palliative care. N Engl J Med. 1997;337:1234-1236. [FullText Link] [Medline Link] [CINAHL Link] [Context Link]

18. Orentlicher D. The Supreme Court and physician-assisted suicide. N Engl J Med. 1997;337:1236-1240. [FullText Link] [Medline Link] [CINAHL Link] [Context Link]


http://gateway2.ovid.com/ovidweb.cgi

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25. Nash A. A terminal case? burnout in palliative care. Prof Nurse. 1989,4:443-444. [Medline Link] [CINAHL Link] [Context Link]

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