Changing Perspectives on Palliative Care

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In the United States, hospice and palliative care are two distinct expressions of the hospice interdisciplinary team approach to end-of-life care, which originated in Great Britain in the 1960s. The hospice movement developed largely as a home-care program and alternative to conventional care.

Although the hospice movement in the United States began as a grass-roots, antiestablishment approach to end-of-life care and was often highly critical of oncology practices, the development of a more academic and medically mainstream palliative-care movement promises greater integration of hospice approaches into oncology and other areas of clinical medicine. Palliative care is based on the hospice philosophy that emerged from Great Britain in the 1960s, in which an interdisciplinary team approach was employed to provide comprehensive patient and family care. Unlike hospice care, palliative care is not meant to be available only when patients meet specific eligibility requirements, such as having an expected survival of less than 6 months or choosing to forego conventional oncologic treatments. The key goals of palliative care—pain and symptom control, psychosocial and spiritual support for the patient and family, informed decision-making,[1] and coordinated services across the continuum of care—are often important at the earliest phases of a fatal, progressive illness, and typically become more important or even an exclusive goal as the disease progresses. Palliative care, therefore, can be practiced alongside oncology and other fields of medicine.

Palliative Care and Oncology

Palliative care is defined as comprehensive, interdisciplinary care, focused primarily on promoting quality of life for patients with a terminal illness and for their families.[2] Based on the hospice philosophy that emerged in England in the 1960s, most notably at St. Christopher's Hospice in London, this approach to end-of-life care includes the following key features:

- meticulous symptom control.

- psychosocial and spiritual support for the patient and the family, including bereavement care for the survivors.

- the fostering of information-sharing and professional guidance in the development of a care plan that reflects the patient’s personal values and goals.

- a team approach involving physicians, nurses, social workers, chaplains, and volunteers.

- sites of care alternative to the usual acute-care hospital, such as hospice home care, but including inpatient hospices or similar institutional settings that promote a homelike atmosphere.

- the provision of coordinated services across the continuum of care.

The term "palliative care" is commonly used as a synonym for end-of-life or terminal care and may
be viewed as an alternative to curative or life-prolonging treatments, as in speaking of comfort or supportive care when aggressive care has failed. However, palliative care has an important role in all phases of a progressive, fatal illness, and should be viewed as complementary to and compatible with management strategies focused on eradicating an illness or slowing its progression. For example, good pain control and the assessment and treatment of depression or anorexia/cachexia are appropriate whenever these symptoms emerge during the course of a fatal illness, regardless of other strategies used to eradicate the underlying disease.

Indeed, some cancer therapies that were introduced as potentially curative or life-prolonging have been shown to primarily improve quality of life, and may be described as palliative. Certainly, palliative care has a more prominent role in the last phases of a terminal disease, but no clear transition occurs between aggressive and palliative management.[3] A true transition to hospice or comfort care occurs only when palliative care becomes the sole focus of care.

Palliative Care in the United States

The best known example of palliative-care principles in the United States is found in the hospice setting. Hospice became a benefit under Medicare in 1982 and now is a regular, although somewhat underutilized feature of most health insurance plans. As of 1999, the National Hospice and Palliative Care Organization reported that more than 3,000 hospice programs were operating across the United States. Of the nearly 2.4 million Americans who died in 1999, roughly 700,000 (29%) received hospice services.

At present, hospices care for more than half of all Americans who die from cancer. Increasing numbers of patients with nonmalignant terminal illnesses, such as end-stage heart or lung disease, liver and renal failure, and acquired immunodeficiency syndrome are referred to hospice care. Unfortunately, most receive only a few weeks of hospice services.[4]

In response to the perceived lateness of hospice referrals, "bridge programs" have emerged over the past 5 to 10 years. These programs offer hospice-like care to patients and their families but do not use the limited hospice admission criteria, such as having a probable life expectancy of 6 months or less; forgoing all aggressive, expensive medical interventions; favoring care in the home and having a primary caregiver there; and carrying insurance that covers hospice services.

Also emerging in the past few years are palliative-care programs, typically academic, hospital-based, and led by a physician—in contrast to hospices, which generally are nonacademic, community-based, and predominantly provide nursing services with minimal physician input. Indeed, new palliative-care programs are often part of a medicine or oncology program and may be more closely aligned with the values of oncologists. Palliative-care programs typically reside in acute-care hospitals or subacute-care facilities, and offer consultative services as well as direct patient care in a dedicated inpatient unit or scattered beds, plus outpatient care and home care.

Palliative Care/Oncology Overlap

Much of an oncologist’s work is palliative, especially when viewed with the above definitions in mind. Between 1985 and 1991 at the British Columbia Cancer Agency, 46% of all radiation therapy courses were deemed palliative.[5] Similarly, much chemotherapy is palliative. According to a prospective survey in a large teaching hospital,[6] almost a quarter (23%) of cancer admissions were for palliative care, either alone or in combination with another aspect of care. Palliative-care activity accounted for 34% of daily bed use, compared with 32% for the administration of chemotherapy. In one series, at least 7% of all cancer patients received strictly palliative chemotherapy.[7] Certainly, palliative-care education needs to be included in the training of all oncologists.[8]

MacDonald[9,10] suggests that palliative care, like many other aspects of cancer control, should be regarded as an exercise in prevention, as a means of avoiding suffering by recognizing and treating as early as possible, the symptoms associated with cancer. An optimal continuum of cancer care, he suggests, recognizes that a mix of therapies should be used to treat both the disease and the symptoms. These therapies are continually modified as the disease progresses, symptoms change, and the goals of care are renegotiated. Indeed, the same therapy may be used to attain
different outcomes at different stages of a disease.

**Progress in Palliative Medicine**

The evolution of both oncologic and palliative-care practices and their cross-fertilization have already changed the manner in which the two fields relate, and will continue to do so. In clinical situations in which any oncologic treatment has little value, even at the onset of a recognized illness (eg, in patients presenting with widespread metastatic solid tumors, advanced hematologic malignancies, or a poor performance status due to the cancer or comorbid conditions), palliative care may immediately assume a major role in patient care. The development of more effective cancer treatments or the use of bone marrow transplantation for some malignancies and for older patients may mean that palliative-care teams assume a significant role later in the course of the disease.

Just as oncology and medicine have continued to evolve since the birth of the hospice movement, so too have pain and symptom management and psychosocial and spiritual care. For example, pain management has improved with the development of clear guidelines on the use of analgesics, the advent of new formulations of opioids and nonsteroidal anti-inflammatory agents, greater appreciation of the role of neuropathic pain and approaches to its treatment, wider availability of programmable infusion pumps, and selected use of epidural drug administration. Similarly, improvements in the management of other symptoms are evident with the introduction of new antiemetics, antidepressants, and major tranquilizers, the use of octreotide (Sandostatin) for small bowel obstruction, and a greater appreciation of the value of psychostimulants and glucocorticosteroids in end-of-life care.

Even a brief description of the progress in palliative medicine is beyond the scope of this review, but we have focused on a few areas that may be discussed less commonly by oncologists: artificial nutrition, malignant small bowel obstruction, communication skills, and ethics.

**Role of Artificial Nutrition**

A number of studies of the risks and benefits of artificial enteral nutrition have changed our understanding of the utility of tube feeding and of the management of a variety of conditions in which oral nutrition is impaired.

To provide comfort for the dying patient, the administration of food and fluids beyond what the patient requests is unnecessary. McCann et al conducted a prospective study in terminally ill patients designed to ascertain whether limiting food and fluids to that which is specifically requested had an adverse effect on quality of life.[11] Patients generally did not experience hunger, and those who did needed only small amounts of food to alleviate the sensation. Complaints of thirst and dry mouth were relieved with mouth care and sips of liquids in volumes far smaller than what would be needed to prevent dehydration.

Nutritional supplements, including total parenteral nutrition, do not benefit patients with advanced cancer who have an intact digestive tract.[12] Glucocorticosteroids and progestational drugs, such as megestrol acetate (Megace), probably provide little or no benefit in terms of morbidity or longevity.[13] According to data from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT),[14] enteral feeding and hyperalimentation were associated with decreased survival in acute respiratory failure, multiorgan system failure with sepsis, cirrhosis, and chronic obstructive pulmonary disease; had no benefit in study patients with cancer; and only seemed to have a beneficial role in comatose patients. Experience with tube feeding in patients with dementia suggests that percutaneous gastrostomy does not reduce the risk of aspiration, but may, in fact, increase it, while rarely prolonging survival in elderly patients.[15-17]

Tube feedings and partial or total parenteral nutrition are often initiated to alleviate the anxiety of patients and their families.[18] Patients and families, as well as health-care professionals, need to be aware that loss of a normal appetite is commonly seen in dying patients and does not substantially contribute to their suffering. Caregivers should use their time and energy to provide comfort and support to these patients, and not to implement artificial nutrition and hydration.[11]
Artificial nutrition has an obvious role in patients with a relatively long predicted survival and good quality of life but who cannot maintain adequate fluid or nutritional intake—for example, patients with severe mucositis or tumors of the oropharynx and esophagus. In these patients and others, any decision to initiate or withhold artificial nutrition and hydration is not necessarily final.[19] Decisions to initiate or maintain artificial feeding require ongoing review of their efficacy, as do all other therapies.[20]

**Malignant Small Bowel Obstruction**

Studies of conservative management of malignant small bowel obstruction[21] indicate that many patients with this condition can be managed comfortably with oral fluids, perhaps supplemented by intravenous or subcutaneous fluid administration but without insertion of a nasogastric tube (a procedure that patients rank highest in discomfort).[22] Judicious use of opioids and antispasmodics can readily control abdominal discomfort, while nausea and vomiting can be relieved with the usual antiemetics. Some patients prefer to eat and vomit periodically rather than the conventional "nothing by mouth" regimen. The addition of octreotide[23-25] can reduce small bowel fluid output, cramping, pain, nausea, and vomiting.

**Changing Perspectives on Communication Tasks**

A variety of recent studies have documented physicians’ difficulties in talking with patients about end-of-life care.[26-29] Key areas of concern include truth-telling, breaking bad news, prognostication, advanced-care planning, recognizing depression and confusional states, and negotiating treatment goals.

Many observers have suggested that the oncologist's preoccupation with conquering cancer has been associated with a sense of failure when death approaches and a reluctance or difficulty in refocusing efforts from cure or prolonging life to improving quality of life. Indeed, a recent survey of members of the American Society of Clinical Oncology indicated that those who had difficulty communicating with patients at the end of life were more likely to see themselves as having failed the dying patient. This, in turn, was associated with a tendency by the oncologist to prescribe chemotherapy in the terminal phase of illness.[30] From the palliative-care perspective, a strenuous focus on cure can detract from the oncologist's potential for being enormously helpful to patients and families in making the best of remaining time.

**Information Sharing**

Based on a variety of studies and societal changes, truth-telling in the doctor-patient relationship has become the norm in the United States over the past 40 years. Recent research has stressed that this practice is culturally based and should be applied sensitively and flexibly.[31] In certain cultures, information is supposed to be shared with the family rather than the patient, and bad news may be routinely withheld from the sick and dying. Thus, frank disclosure of a cancer diagnosis, advancing disease, or the imminence of death, based on the ideal of promoting informed decision-making, has been tempered by the awareness that strong objections to such practices exist in some populations.

These caveats should not be interpreted as a license to avoid difficult conversations, because most patients desire more information regarding their illness and treatment options and more of a role in planning their care than physicians tend to offer.[32-35] Moreover, cancer patients and their families typically regard their physician as the primary source of cancer-related information[36-38]; without good information, they may overestimate the life-prolonging benefits of chemotherapy, confounding its use with their hopes for a cure or prolonged survival.[39,40] Physicians should make a reasonable effort at the outset of any treatment to share with patients and their families the reasons for inaugurating or discontinuing therapy.[41]

The quality and timing of such information is associated with important clinical outcomes, such as patient satisfaction and psychological adjustment.[42-44] Good communication skills may also be important for the psychological health of physicians.[45]
Recognition of Patient Preferences

The results of the SUPPORT study, which involved more than 9,000 selected patients (including 16% with cancer) admitted to five different medical centers, surprised many clinicians. In particular, the study demonstrated that physicians’ ability to describe the preferences of their acutely ill patients for life-sustaining therapy was no better than chance, even when prompted by written communication from specially trained nurses.[26]

Dying patients and their families generally want compassionate physicians to guide them through the dying process.[46] Decision-making is not left solely to the patient, the family, or the health professional, but reflects a process of information and value sharing, which, in turn, leads to negotiations about treatment. Yet, physicians seldom initiate discussions about the goals of medical care at the end of life.[47,48]

Advance-Care Planning

In three separate studies,[49-51] a mismatch was noted between patients’ wish to discuss end-of-life issues with their physicians and what actually took place. Emanuel et al.[52] documented that 70% of patients knew about living wills and 92% wanted to be involved in advance planning. However, few patients actually completed advance-care directives.[53] Moreover, patient preferences regarding end-of-life care may change over time. Therefore, the goals and methods of care and associated advance-care documents need to be reviewed regularly.

Great interest and hope have been placed on living wills and other forms of advance-care planning to give patients some control over their medical management should they become unable to express their informed choices. Studies of the use of advance-care documents have been almost uniformly disappointing, with the exception of a community-wide intensive effort to promote the practice[54] and a vigorous program in a single nursing home.[55]

In general, patients do not have advance-care directives, proxies do not understand the patient’s wishes, living wills or similar documents that have been completed are unavailable to clinical staff when needed, and physicians tend to do what they believe is right, even when special efforts are made to communicate the patient’s wishes. Nevertheless, identifying a proxy for all patients, especially when the patient is still well, and encouraging patients to discuss their care preferences with the proxy, is widely endorsed.[56]

Do-Not-Resuscitate Orders

A similar set of attempts to establish do-not-resuscitate (DNR) orders prior to a medical crisis have proven largely ineffective. Indeed, the DNR order has been relegated to a ritual of allowing a patient to die when physicians feel that further life-sustaining measures are inappropriate. In the modern hospital, the DNR order serves as an instrument for obtaining consent from patients or their families to discontinue supportive measures and is requested typically in the last few days of life, rather than serving as a treatment guide throughout a hospitalization.

Volicer has described a highly successful process for deciding whether to limit care in an advanced-dementia patient, compared to conventional management using DNR status.[18] This approach relies on the slow, relatively predictable downhill course of Alzheimer’s disease, but might also reasonably be applied to a cancer patient.

Bereavement

Palliative care does not end with the death of the patient. Not all families require bereavement counseling, but many will benefit from simple supportive measures, and a few should be identified (through systematic screening) for sophisticated interventions. Good bereavement care can prevent the substance abuse that leads to premature death among survivors and can improve the family’s psychosocial well-being and satisfaction with care. Bereavement follow-up in acute-care hospitals is notably deficient and haphazard.[57] Hospices offer 13 months of follow-up for bereaved families.

A similar pattern of providing condolences, offering routine bereavement services, monitoring and assessing grief, and assuring timely referral for selected grieving relatives should be part of any palliative-care or oncology program.[58] The education and training of all physicians should also
include attention to topics such as medical determination of death, preparing the body, notifying the
family, documenting the death in the medical record, completing a death certificate, reviewing the
medical care with colleagues, following-up with the family, and opportunities for reflecting on
personal reactions to the death.

Improving Communication

**Physician Education** Although some may argue that humane attitudes and good communication
skills are innate, studies by Maguire,[59] Baile,[60] and others indicate that these traits can be
taught to clinicians. Communication skills workshops may be useful in providing training to
oncologists on the stressful aspects of the physician-patient relationship.[61]

Workshops for practicing oncologists, as well as basic oncology training, should address the
challenge of good physician-patient communication and acknowledge the influence of fear of death
on those who become physicians.[62,63] It is also important to teach oncologists that a patient’s
terminal suffering can be alleviated and that the period before death can be a rich and rewarding
opportunity for communication among physicians, patients, and families.[64,65]

**Organizational Change** Implementing an effective intervention based on a normative model of
shared decision-making can be quite difficult. Practice patterns and social expectations may strongly
influence the course of a patient’s care. Powerful psychological and social forces underlie current
practices. System-level innovation and quality improvement in routine care may offer more promise
for improvement.[29]

**Ethical Principles, Ethical Dilemmas**

Decisions about care at the end of life place a significant emotional burden on health-care providers,
as well as on patients and families. About half of the providers surveyed by Solomon et al reported
that they had acted against their conscience in providing care to the terminally ill, and four times as
many felt that they had provided overly burdensome care rather than undertreatment at the end of
life.[66] Mechanical ventilation, CPR, dialysis, artificial nutrition, and hydration were felt to be
overused, whereas pain relief was felt to be suboptimal.[66]

The notion that competent, well-informed patients have the right to stop life-sustaining treatments,
even when death is the immediate consequence, is widely accepted among both medicolegal and
bioethical experts.[67-69] This right is extended to surrogate decision-makers for incompetent
patients. However, not all clinicians accept these principles, and the clinicians who subscribe to such
ideas may not practice them resolutely or consistently.

Fine and Mayo[70] have described a new Texas law that attempts to address the familiar situation in
which clinicians feel forced to provide care that they consider medically inappropriate or even futile
to a terminal or irreversibly ill patient whose family insists that "everything be done" to avoid death.
When the medical staff recommends withdrawal of care, family members sometimes see this as a
request to be allowed to kill the patient. Under the Texas law, the negotiation process involves
consultation with an ethics or medical committee, the option of family participation in such
deliberations, and, if the committee concludes that treatment is medically inappropriate by
community standards, giving the family 10 days to transfer the patient, appeal to the courts, or
accept that life support will be withdrawn. Along with rarely documented instances in which futile
care or care deemed medically inappropriate has been refused by providers,[71] this law offers an
antidote to the current practice of always giving family members the right to approve difficult
treatment decisions.

**Ethical Distinctions About Hastening Death**

To restore a balance between the physician’s obligation to prolong life and the obligation to relieve
suffering, a peaceful death must be acknowledged as a legitimate goal of medicine and an integral
part of a physician’s responsibilities.[72] The use of life-support systems in severely ill patients has
become standard practice in medical care and has redefined what used to be a clearly terminal
situation into one in which life can be prolonged for sometimes lengthy periods.[73] Indeed, few chronic illnesses progress to death without a number of decisions being made about the use of life-prolonging measures.

Many medical professionals believe incorrectly that a decision to forego life-sustaining treatment is equivalent to active euthanasia.[74-76] Such beliefs may push health-care professionals to use any technology that might prolong life or to avoid starting treatments that one might later wish to stop.[72] Even clinicians who understand the ethical distinctions between withholding or withdrawing care, the principle of double effect (see below), assisted suicide, and voluntary euthanasia—arguably difficult distinctions under some circumstances—may appreciate that almost all acts that hasten death can be difficult and potentially upsetting to health professionals. Indeed, one can be grateful that clinicians do not treat such matters lightly.

Double Effect

—The principle of double effect is widely accepted and extremely helpful in thinking about some end-of-life situations in which physician-assisted suicide or euthanasia might be considered. According to this principle, when the goal of care is comfort, treatment may be provided with the understanding that it may hasten death as long as the intent is primarily to provide comfort.

For example, a dose of analgesics or sedatives may be administered to control pain or shortness of breath in a terminally ill person despite the fact that the medication may accelerate dying, as long as the purpose of the medication is comfort and the unintended side effect is acceptable. Even critics of the rule of double effect[77,78] encourage liberal use of opioids and sedatives to control pain, dyspnea, or emotional distress in the terminally ill—a practice that can ensure relief of suffering yet is considered distinct from euthanasia.[79]

Stopping Food Intake and Terminal Sedation

—Two additional approaches have been suggested for providing a comfortable, safe death for terminally ill patients who are facing intractable suffering and wish to hasten their demise. Voluntarily refusing to eat or drink, especially with the medical staff promising that any discomfort will be managed with liberal use of medications, has been recommended so that patients may hasten their death without the need for a physician’s direct assistance.[80]

Other authors have endorsed what has been misleadingly coined "terminal sedation" or, more accurately, "sedation for intractable suffering of a dying patient,"[81] whereby a terminally ill person with irremediable suffering is sedated to unconsciousness. If fluids are not provided to such an obtunded patient, death soon ensues.

With an awareness of these two options, plus routine comfort measures, the right to withhold or withdraw supportive measures (including fluid and nutrition), and the principle of double effect, physicians are better able to respond to a "bad death" as a medical emergency.[82]

Physician-Assisted Suicide and Euthanasia

—No aspect of palliative care has received as much attention recently as the ethics and possible legalization of physician-assisted suicide for terminally ill patients. Inadequate control of distressing symptoms in the terminally ill[76] may contribute to the public’s increasing desire to legalize physician-assisted suicide.[83-85]

Of US oncologists surveyed, 22.5% supported the use of physician-assisted suicide in dying patients with unremitting pain, and 6.5% supported euthanasia.[86] Oncologists who were reluctant to increase the dose of intravenous morphine in these patients and had sufficient time to talk to them about end-of-life care issues were less likely to support euthanasia or physician-assisted suicide. Oncologists who reported not being able to provide all the care that a dying patient needed were more likely to have performed euthanasia.

Between 1994 and 1998, oncologists’ support for physician-assisted suicide in the prototypical case of a terminally ill patient with unremitting pain declined by half, from 45.5% to 22.5%. Similarly, support for euthanasia has declined by almost three-quarters, from 22.7% to 6.5%.[87,88] This decline may reflect expanding knowledge about how to facilitate a "good death," thus making euthanasia and physician-assisted suicide no longer necessary or desirable.[89] Physicians who
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reported receiving better training in end-of-life care seemed less likely to perform euthanasia or physician-assisted suicide.[53] Such physicians may also feel more capable of providing optimal palliative care without resorting to these extreme measures.[89,90]

Insofar as data guide the debate on physician-assisted suicide and its legalization, practical experience in the Netherlands[91] and the state of Oregon[92] sheds light on the subject. As many as 60% of dying people who express a wish to hasten their death are depressed, and hence, have treatable and potentially reversible suffering.[93] In the first 14 months after physician-assisted suicide was legalized in Oregon, fewer than two persons a month (less than 1% of persons who died) requested and received a prescription for lethal medication, and only about half of these individuals used the prescription.[94] Physicians granted 1 in 6 requests for a lethal medication, and only 1 in 10 resulted in a suicide.[92]

Conclusions

The aim of palliative care is to achieve optimal quality of life for patients and their families in the face of a life-threatening illness. Symptom control and psychosocial and spiritual support by an interdisciplinary team are becoming the norm for good terminal care and the definition of "best supportive care."[95] Palliative-care programs are developing throughout the United States and striving to be integrated with other elements of cancer control. Advances in palliative care need to be incorporated into oncology practice, and thus will require changes in oncology services and education. Research into palliative-care practices and new models of delivering and financing end-of-life care in a variety of settings will also be required.

References:


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