Completing the Continuum of Cancer Care: Integrating Life-Prolongation and Palliation

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Abstract
Cancer care extends from diagnosis through the late stages of advanced illness as patients confront dying and their families cope with caregiving and grief. Palliative care is a rapidly developing area of clinical focus that offers valuable services to patients in terms of symptom management and adjustment to illness, including issues of life completion and life closure. It is often appropriate to offer certain elements of palliative care early in the course of illness. As disease progresses, physical comfort and enhancing quality of life increasingly become primary goals of cancer care. Specialized palliative care programs, epitomized by hospice, are invaluable resources for patients with far-advanced illness and their families. Current regulations and prevailing payment structures limit access to and the scope of hospice services and highlight the need for innovative models of delivering and financing palliative care. (CA Cancer J Clin 2000;50:123-132.)

Introduction
Clinicians working in the field of oncology routinely encounter patients whose illness progresses despite intensive efforts to extend life. While there have been important advances in cancer care over the past several decades, and recent remarkable progress in treating a few specific neoplasms, approximately half of all current cancer patients will eventually die as a consequence of their illness or related complications. Caring for people as they die is, therefore, an integral part of oncology practice.

During the latter half of the 1990s, a series of studies documenting serious deficiencies in symptomatic care of patients with far advanced illness and the public debate over legalization of physician-assisted suicide have dramatically raised professional and public awareness of the urgent need to improve care for dying persons.

Physicians have cared for dying patients from earliest antiquity. Given the sophistication of contemporary medicine, it seems ironic that this core clinical responsibility has never been more difficult for physicians to discharge than it is today. In part, the current perplexities of caring for people as they die derive from the dramatic advances in curative and remissive treatments. Illnesses, such as cancer, that would have quickly ended life as recently as the first part of the 20th century can now be well treated and, even those that cannot be cured, are often satisfactorily managed for years. The phenomenon of chronic illness with an associated prolonged period of decline is now a prevalent trajectory of dying. Indeed, a large majority of people living today can anticipate dying at an advanced age, from consequences of a disease with which they have lived for months to a number of years.

In the report of its comprehensive study of the state of end-of-life care in America, the Institute of Medicine concluded that serious deficiencies exist in clinical practice, in professional training, and in the resulting attitudes and assump-
tions of professional caregivers. The study also noted inadequacies in the existing scientific evidence base for palliative care and acknowledged obstacles that diminish access to and quality of end-of-life care arising from existing health care policy, financing, and modes of health care delivery (Table 1).2 The report by the Institute of Medicine concludes with a set of recommendations that respond to these deficiencies (Table 2).

Consistent with these recommendations, the American Society of Clinical Oncology (ASCO) recently approved a statement of policy and principle entitled, “Cancer Care During the Last Phase of Life.”3 This important document repeatedly emphasizes the multidimensional nature of the illness experience and stresses the importance of continuity as a principle of cancer care.

“The American Society of Clinical Oncology believes that it is the oncologists’ responsibility to care for their patients in a continuum that extends from the moment of diagnosis throughout the course of the illness. In addition to appropriate anticancer treatment, this includes symptom control and psychosocial support during all phases of care, including those during the last phase of life.”3

This statement calls to mind the anonymous adage from the Middle Ages: “To cure sometimes, to relieve often, to comfort always,” which succinctly and powerfully conveys the essential principles of the clinician’s role.4

**Caring for Patients As They Die**

The principal responsibilities of physicians to dying patients are straightforward. Symptom management is primary. The nature of being mortal guarantees that there will come a time in each person’s life when death will prevail. Medicine cannot always prolong life, but contemporary knowledge and medical skills can assure people of being protected from extremes of physical distress. In far-advanced illness, when cure is no longer possible and extension of life is increasingly difficult to achieve, relief of physical distress becomes the highest priority.
PAIN RELIEF

Pain is the cardinal symptom associated with advanced cancer. In common discussion, the word “pain” often is used to symbolize a range of symptoms, such as dyspnea, fatigue, confusion, nausea, tenesmus, dizziness, and itching, all of which can cause suffering among dying patients. Emotional symptoms, such as anxiety and depression, are also all-too-common sources of suffering.

Satisfactory control of symptoms can usually be achieved with a direct, organized approach. First, when feasible,

Table 2
Recommendations and Future Direction

| (Conclusions of the Committee on Care at the End of Life, Institute of Medicine, 1987)² |
| 1. People with advanced, potentially fatal illnesses and those close to them should be able to expect and receive reliable, skillful, and supportive care. |
| 2. Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms. |
| 3. Because many problems in care stem from system problems, policy makers, consumer groups, and purchasers of health care should work with health care practitioners, organizations, and researchers to: |
| a. strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them. |
| b. develop better tools and strategies for improving the quality of care and holding health care organizations accountable for care at the end of life; |
| c. revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care; and |
| d. reform drug prescriptions laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering. |
| 4. Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients. |
| 5. Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research. |
| 6. The nation’s research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care. |
| 7. A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death. |

From Field MJ, Cassel CK (eds)²
treatment is directed at ameliorating the pathophysiology of the illness. Additionally, analgesics and analgesic adjuvants can diminish the experience of nociception. While eliminating all discomfort arising from extensive, multi-system illness may not be possible, through assiduous evaluation, attention to detail, careful explanation, and continuous monitoring, physical distress among dying patients can always be alleviated.

Even in those rare situations in which extremes of pain, air hunger or agitation persist despite intensive, multimodal interventions, the use of sedative medications can provide reliable relief of physical distress (see Cherny, page 70). Pharmacologic sedation can be employed pending interventions such as nerve blocks, surgical neurolysis, or fixation of long bone fractures. When death is imminent, sedative medications can be continued along with meticulous nursing care through the patient’s demise.

EMOTIONAL ISSUES

While physical comfort is the first priority in treating a dying patient, it is not the only goal. Psychosocial and spiritual or existential distress are, of course, also common among dying persons and clearly demand a caring response. The ASCO statement noted, “The dying process creates a myriad of questions and concerns about the meaning of life. People confront and resolve these questions and concerns in their own ways, frequently but not exclusively through religious and philosophical beliefs. Increasingly, those who care for the dying find that spiritual and existential issues are central to the quality of patients’ lives as they near death.”

ASCO repeatedly emphasizes hospice care as an important and underutilized resource in its statement on caring during the last phase of life. “ASCO believes that hospice is a widely available and excellent model for managing end-of-life care and should be better utilized... As the best available model of end-of-life care, hospice must be positioned as a valid, therapeutic alternative to continuing futile, disease-oriented therapies.”

The Role of Hospice in Caring for Cancer Patients

Hospice is hardly a new phenomenon. In the US, the first hospice program was established in 1974. Currently, there are more than 3,000 licensed hospice programs, serving over 450,000 patients a year.

In the 1994 Standards of a Hospice Program of Care, the National Hospice Organization defined hospice as a model for providing palliative care. “Hospice offers palliative care to all terminally ill people and their families regardless of age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay.”

The statement continues by defining palliative care in terms of its goals. “The National Hospice Organization defines palliative care as treatment that enhances comfort, and improves the quality of the patient’s life.”

This characterization is consistent with a seminal World Health Organization (WHO) technical report on cancer pain relief that defined palliative care as, “The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of illness in conjunction with anticancer treatment.”

GOALS OF ONCOLOGY AND PALLIATIVE CARE

As can be seen from such statements, the goals of oncology and palliative care are...
well aligned. Palliative care represents a valuable set of specialized services that complement ongoing physician-directed care aimed at disease-modification and comfort. Hospice has epitomized palliative care for patients with far-advanced illness. Hospice programs gather physicians, nurses, and professionals from clinical social work, pastoral care, pharmacy, the supportive therapies (physical, occupational, respiratory, and dietary) together with home health and bath aides into an interdisciplinary team dynamic and collaborative process of care. Each team member brings the perspective and expertise of his or her discipline, as well as a unique personal and clinical experience, contributing his or her efforts and talents to the goals of comfort and improving the quality of the last phase of a cancer patient’s—and family’s—life.

Hospice programs also draw upon a pool of trained and supervised volunteers to offer a myriad of mundane yet essential services. Volunteers also offer companionship. In the midst of the inherent loneliness and isolation of dying, hospice volunteers listen and bear witness to the individual’s fears, disappointments, and triumphs.

BEYOND SYMPTOMS AND SUFFERING: LIFE REVIEW

While clinicians must attend to the multiple sources of discomfort and despair among the dying, the experience of living with progressive, life-limiting illness cannot be understood solely through a framework of suffering. Beyond the inevitable problems of terminal illness, this waning phase of life also encompasses opportunities for life review, life completion and meaningful closure that can profoundly enrich the quality of the person’s remaining days—and affect the lives of family members for many years to come.\(^\text{14}\)

Compared with a sudden death, dying of progressive illness offers a chance not to leave things “undone” and to do what is necessary to put one’s affairs in order. An anticipated death affords the opportunity to reconcile previously strained relationships and a chance, once again, to tell one’s treasured stories.

As the activities and responsibilities of busy life fall away during progressive physical and functional decline and as life’s end looms ever closer, it is common for people to explore questions of ultimate meaning. Issues surrounding the existential dimensions of life and death are not only sources of suffering. In exploring the place of human beings in the universe and questions related to the existence of a caring god or of an afterlife, many people find spiritual comfort and strength. Matters of this nature are on the minds of many seriously ill patients. In striving to support people in this realm of life, the clinician’s role is not to provide answers; rather, it is to listen and help people find their own answers. Here, too, hospice teams offer a valuable service.

One of the precepts of palliative care is that dying is considered a normal stage in the lives of individuals and families.\(^\text{12,15}\) A developmental approach to this stage of life offers a perspective from which clinicians can assist people in identifying ways of working toward a self-determined sense of completion in personal, interpersonal and spiritual realms of life.\(^\text{14}\) Within this framework, sources of emotional and spiritual distress can be explored and care planning can incorporate a focused response without the experience of the patient or family requiring a diagnosis of psychosocial pathology.

An important monograph from the Standards and Accreditation Committee of the National Hospice Organization outlines a “treat, prevent, promote” intervention strategy. In approaching a dying person and family, the most immediate responsibility is to treat immediate sources of suffering, whether they are physical, emotional, social, or spiritual. Next, the team focuses on preventing foreseeable problems and complications. Finally, the palliative plans of care also
include opportunities that promote growth for patients and families, individually and together, during this final stage of life.16

ACCESS TO HOSPICE
The best hospice programs have collectively established benchmark practices and clinical outcomes against which other models of palliative care can be assessed. However, hospice has not been immune from problems of access, uneven quality and limitations of service imposed by financial constraints that plague the US health care system.

As recognized by the Institute of Medicine report and the ASCO statement, currently hospice is an underutilized resource in the care of people with advanced, incurable illness. When the Medicare Hospice Benefit was adopted by Congress in 1982, an appropriate length of hospice service was anticipated to be in the range of six months. Recent data reveal that average lengths of stay are in the range of just 30 to 45 days and median lengths of service are as low as two weeks.17,18

Many physicians remain only minimally familiar with hospice services, and tend not to refer patients who, with their families, would benefit from the services hospice offers, or who refer very late, often just days before a patient’s death. Patient attitudes, fears, and misconceptions heavily contribute to these referral and utilization patterns. Even when the far-advanced extent of illness is acknowledged and despite full disclosure of the risks of continued life-prolonging therapy, many patients actively resist a referral to hospice opting, instead, to pursue aggressive disease-modifying treatment.

Oncologists often are in a critical position to assure people that hospice does not mean abandonment. Physicians can give evidence of the continued importance of their relationship with the patient and the continued value of the patient’s life most basically by listening to peoples’ fears and sadness. It is appropriate for clinicians to express their own disappointment and sadness at the progression of illness and to emphasize their continued commitment to caring. Within this context, referral to hospice can be introduced as an expansion of resources and caring people, as well as a higher level of support.

CURRENT LIMITATIONS OF HOSPICE IN THE US
Although in principle, life-prolonging and palliative care should be well-integrated in a smooth continuum of care, the current payment and delivery systems impose barriers to this goal. While the Medicare Hospice Benefit and the companion Medicaid Hospice Benefit that exist in most states have fostered dramatic growth of hospice, they have limited the scope of hospice services and contributed to a fragmented system of care.18 Federal oversight of the Medicare Hospice Benefit has focused on ferreting out fraud and abuse, through Focus Medical Review and through Operation Restore Trust, an investigation conducted by the Office of the Inspector General (OIG) of the Department of Health and Human Services.19-21

The OIG ultimately concluded that instances of frank abuse are rare and that, “overall, the Medicare hospice program seems to be working as intended.”22 Nevertheless, Operation Restore Trust has had a limiting effect on patients’ access to hospice and, therefore, to palliative care. Commenting on the OIG final report, Karen Davie, President of the National Hospice Organization, expressed the dismayed perspective of the hospice programs in observing that, “The OIG’s intense scrutiny has had a chilling effect on appropriate referrals of terminally ill beneficiaries and resulted in gross under-utilization of hospice services.”23

Yet problems with access stem from more than just a reluctance on the part of referring physicians. Many hospice pro-
grams, perceiving a threat of retroactive
denial of payment or even stiff fines for
having patients live too long, have be-
come more selective in accepting pa-
tients. Programs may be reluctant to ad-
mit patients whose principal diagnosis is
characterized by slow, progressive de-
cline, despite serious disability (such as in
Alzheimer’s dementia) or those whose
disease course is marked by life-threaten-
ing exacerbations interspersed between
periods of relative stability, such as in
congestive heart failure or chronic pul-
monary disease.24

This tragic trend impacts care of pa-
tients with cancer as well. As advances in
oncology offer valuable palliative options
to extend and improve quality of life for
patients with far advanced illnesses such
as ovarian cancer, breast carcinoma, and
certain lymphomas, existing regulations
and payment structures limit access to the
comprehensive programs of palliative
care that hospices represent.

Another adverse effect of the pre-
vailing regulatory and payment structure
is the limitations that are placed on the
scope of hospice services and, by exten-
sion, the scope of palliative care available
to patients. The capitated, per diem pay-
ment structure of the Medicare Hospice
Benefit makes no allowance for case mix
adjustment and, therefore, imposes se-
vere financial strains on hospice pro-
grams when patients require extremely
expensive palliative interventions. In the
pursuit of comfort and quality of life, ap-
propriate care should exclude no inter-
vention based on intensivity or cost. Ide-
ally, the only test lies in the balance of
risks to potential benefits in terms of ad-
vancing the patient’s own goals. Under
existing payment structures, however, the
costs of important palliative interven-
tions, such as external beam radiation
therapy, injectable radioisotopes, use of
colony stimulating factors, 5-HT3-recep-
tor-blocking antiemetic agents, neurolytic
blocks, and surgical procedures, can
threaten the very survival of hospice pro-
grams, especially smaller programs. It is
ironic that at present, patients may be
forced to decline or even revoke hospice
services to be eligible to receive these
valuable and therapeutically appropriate
palliative interventions.

Beyond the Dichotomy

Acknowledging the imperfection of the
world in which we live and the systems in
which we practice, physicians are, never-
theless, challenged to provide the best
care possible for patients and their fami-
lies. In the prevailing “real world” con-
text of practice, advocacy and coordina-
tion of services and care are critically
important roles for the health care team.

Integrating Palliative and Life-
Prolonging Care

At present, curative therapy and pallia-
tive care are perceived as dichotomous.
Decisions regarding life-prolonging ther-
papy and palliative care tend to be present-
ed in an “either-or” manner. This misper-
ception is reinforced by Medicare reg-
ulations and corresponding requirements
of some health plans and insurance poli-
cies that impose a choice between any
further potentially life-prolonging treat-
ment and the comprehensive programs of
symptom management, supportive care,
aide services, and financial benefits, such
as paid prescriptions, that hospice pro-
grams provide.

As a result, comprehensive palliative
care is often instituted only after life-pro-
longing care is no longer available or has
been rejected by the patient (Fig. 1).13
Within the health care culture, where
cure is the highest value, hospice and pal-
liative care are typically viewed as sec-
ond-rate alternatives, apologetically pre-
sented to patients when better options
are not available. However, the precepts
of palliative care emphasize the impor-
tance of continuity of care and offer
symptom management, skillful com-
munication, and psychosocial support
throughout the course of illness. Correctly understood, palliative care represents a “both-and” model of care (as opposed to “either-or”), in which a smooth transition from mostly curative to mostly palliative interventions is the norm.

The continuum of palliative care, within the overall management of patients with progressive cancer, is well represented by a simple diagram (Fig. 2). As a patient’s disease advances and there is proportionately less to offer in terms of life-prolongation, it is logical that the focus of care should progressively shift toward the goals of comfort and quality of life. Thus, despite the apparent dichotomy resulting from the prevailing reimbursement structures, palliative and life-prolonging efforts well complement one another and can properly proceed simultaneously.

The principle of proportionality, weighing the potential benefits of an available intervention against the risks, underlies the process of care planning and decision making. The values and self-defined goals of the patient, as well as his or her current quality of life form the fulcrum for this ongoing decision-making process.

It should be noted that even at the very end of life, some life-prolonging measures may be warranted if they have potential for advancing the patient’s goals with a risk that is deemed acceptable. These treatments are represented by the area above the diagonal line in the upper right corner of Figure 2. Here again, the potential benefits of a therapy must be weighed against its “costs” in terms of potential discomfort, quality of life, and personal goals. A patient who is bedridden following spinal cord compression from extradural metastases, who is deriving value from her present quality of life despite severe functional compromise, might thoughtfully decline hospitalization or intravenous antibiotics should a future pneumonia or bloodborne infection occur, yet might accept antibiotics by mouth or enterostomy tube. Similarly, and without incongruity, the same patient might request a yearly influenza vaccine, fully understanding that it is a life-prolonging measure, albeit with minimal risk of either discomfort or life-shortening complications.
A Mixed-Management Model of Care

The process of ongoing care planning involving the patient together with his or her family underpins the mixed-management model of care. At each point from diagnosis through death, the patient or surrogate has the right to make informed choices among all indicated and available options for care. By introducing the concept of palliative interventions aimed at comfort and improving quality of life early in the treatment discussions, physicians can begin to support continuity of care that extends through the end of a patient’s life and to the family during bereavement.

Advance care planning includes completion of documents such as a living will, conveying an individual’s preferences for care and a durable power of health care, formally appointing a proxy to make decisions if the person is unable to decide for himself or herself. Increasingly, the term advance care planning is also being used to refer to the iterative process of assessing the patient’s and family’s needs, discussing the risks and benefits of each therapeutic option, and making decisions for the short and midterm future.

Even at the time of diagnosis, physicians must not assume that every patient confronting a serious, life-threatening illness will choose aggressive life-prolonging care. Some patients will carefully consider all options and decide to forgo curative or remissive therapies despite a fair chance of success. The process of informed consent requires active involvement by physicians and the ethics of decision making allow for strong recommendations on the part of physicians. Ultimately, however, it is the patient or appropriate surrogate whose choice among available options must prevail. Patients and families deserve the best information available, in words they can comprehend, and they deserve clinician’s recommendations throughout the course of illness and treatment. Within the ongoing process of care planning, it is the persons served who appropriately determine the proportion of life-prolonging to palliative treatments within the continuum of care at any point in time.
Conclusion

Contemporary palliative care reflects an understanding of dying as an inherent part of life and as a profound personal experience for the individual and family. Clinicians in oncology have essential roles to play in ensuring comfort and enhancing the quality of the dying person’s, and the family’s, life. Pain and other sources of physical distress associated with far-advanced disease can always be alleviated. Suffering that arises from deeply personal and spiritual or existential sources are clinically approachable. The first step is to acknowledge the person’s suffering by listening in a skillful manner. In addition to acknowledging the capacity for human suffering at the end of life, hospice and palliative care recognize dying as a time of remarkable opportunity.

In caring for patients without denying the inevitability of death, by providing care within a team of committed providers, by being fully committed to doing what is necessary to achieve relative comfort, and by acknowledging the lifelong human capacity for growth, clinicians can contribute to a healthy reincorporation of the value of dying within the mystery of life.

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