

Cancer Care During the Last Phase of Life

Adopted on February 20, 1998 by the American Society of Clinical Oncology*

Executive Summary: The American Society of Clinical Oncology (ASCO) 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. In an effort to assure that all patients and their families have access to optimal care at the end of life, ASCO firmly believes it is essential to emphasize a humane system of cancer care based on the following principles:

- Cancer care is centered around the longstanding and continuous relationship between the primary oncologist or other physician with training and interest in end-of-life care and the patient;

- Cancer care is responsive to the patient's wishes and to the parents' wishes if the patient is a child;

- Cancer care is based on truthful, sensitive, empathic communication with the patient, and in the case of pediatric patients, that care is both family centered as well as child focused; and

- Cancer care optimizes quality of life throughout the course of an illness through meticulous attention to the myriad physical, spiritual, and psychosocial needs of the patient and family.

To reach these goals, ASCO has identified numerous obstacles that hinder delivery of high-quality end-of-life care and offers recommendations for improvements. ASCO is committed to informing its membership and the public about the significant barriers to optimal care at the end of life, and advocating legislative and regulatory changes that will eliminate these barriers.

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SCOPE OF THE PROBLEM AND RECOMMENDATIONS

- Clinical barriers to achieving high-quality end-of-life care must be overcome; these impediments include inappropriate attitudes of health care professionals and patients towards death, ineffective communication, fragmentation of care, and lack of availability and/or insurance coverage of high-quality end-of-life care.

To address the clinical barriers, physicians and other health care professionals must develop the specific skills required to ensure high-quality end-of-life care. Physical, psychosocial, and spiri-

tual care must be part of a patient's treatment from the outset and continue through all phases of the illness. Oncologists must learn to recognize and respond to that transition point in a patient's care when disease-oriented anticancer therapy must give way to symptom-oriented palliative therapy. ASCO recommends broader use of multidisciplinary palliative care programs which involve physicians, nurses, pharmacists, psychologists, social workers, child life workers, pastoral care providers, pain specialists, and ethicists. In the case of children, it is imperative that programs recognize the developmental milestones that impact the care of the child and family. In the absence of such programs, physicians involved in the primary care of terminally ill patients should have the knowledge to assess and manage the physical and psychosocial symptoms of patients and their families as well as the knowledge to access the available support services. ASCO believes that the elements of quality end-of-life care developed by the American Medical Association Institute for Ethics represent a high professional standard which should be applied to the care of patients with cancer.

- Economic barriers faced by patients without insurance as well as those who are underinsured pose a major obstacle to receiving optimal care at the end of life.

Reimbursement policies by public payers such as Medic-

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**ASCO sincerely appreciates the contributions of the Task Force on Cancer Care at the End of Life, which devoted much time and effort to this project. Chair: Lowell Schnipper. Members: Jacob D. Bitran, Linda L. Blank, Diane Blum, Dan Brock, Eduardo Bruera, Ezekiel J. Emanuel, Kathleen M. Foley, David S. Gordon, Joanne M. Hilden, Robert A. Kagan, Michael H. Levy, Allen S. Lichter, Michael P. Link, W. Charles Penley, Thomas J. Smith, Karen Stanley, Ellen Stovall, Laurence Kevin Tokaz, William C. Wood, and Robert Mayer.*

Full contact information for members of the Task Force on Cancer Care at the End of Life is listed in Appendix II.

Address reprint requests to Julie Taylor, American Society of Clinical Oncology, 225 Reinekers Lane, Suite 650, Alexandria, VA 22314.

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aid and Medicare, as well as private insurers, should be improved to eliminate the disincentives to physicians to make timely referrals of patients to hospice or other appropriate delivery systems for end-of-life care. Benefits for providing such care should be sufficient to assure the highest quality delivery of end-of-life care, with emphasis on hospice nurse-coordinated managed care as the best model. Insurance standards for these services should be uniform among the various insurers, and special attention should be given to assuring coverage for oral opioids.

- Education of physicians and other health care providers must be improved through development of training programs, formal curricula, and other initiatives.

Educational initiatives must include formal training in pain and symptom management, recognition when anticancer therapy will not help, techniques of palliative care, effective patient/family communication, medical ethics, psychosocial support, and the teaching of leadership skills to physicians in order for them to direct the team of end-of-life care professionals available in various clinical settings. Role models must be identified and used at all levels of medical education. Once developed, these skills must be continually evaluated and recognized. Certifying examinations in the oncology subspecialties must include queries about end-of-life care. ASCO is committed to providing such education opportunities through development of curricula, symposia, educational videos, workshops, and other continuing education activities.

- Research is urgently needed to address the physical, psychological, and socioeconomic issues related to caring for people with terminal illnesses.

AMERICAN CITIZENS have become increasingly concerned and vocal about practical, moral, and philosophical questions that pertain to the final phase of life. We have made some progress in understanding disease with improvements in clinical care and with the promise of even greater advances to come. These successes will beget others if society continues to remain focused on the challenge posed by human diseases. Americans will live longer and healthier lives.

However, death is inevitable. Approximately 50% of all cancer patients do not survive the disease, and scientific progress must not distract us from that penetrating reality. There are proven inadequacies in the way we care for the dying. Patients fear a lonely, painful, inhumane technological attempt to delay or counter forces of nature that cannot be altered, and that the process of their dying will be out of

There must be a significant increase in research on outcomes, predictors, and interventions during the final phase of life. Such research should address pain and other physical symptoms, depression and other mental health conditions, spirituality and existential meaning, communication between physician and patient/parent, and between patient (both adults and children) and family, burdens on caregivers, and economic hardships.

- Hospice is an excellent model for managing end-of-life care and needs to be more effectively utilized.

Hospice care must be given a greater priority as a health care option. As the best available model for end-of-life care, hospice must be recognized as a valid, therapeutic alternative to continuing futile, disease-oriented therapies. ASCO believes hospice should be viewed by physicians and patients as a completion of comprehensive, quality cancer care.

- Physician-assisted suicide (PAS) is the subject of a national debate, the intensity of which obscures the essential problem that many patients do not receive optimal end-of-life care.

ASCO believes that PAS is a complex issue which this Task Force will neither condone nor condemn. Physicians should engage their patients in discussions about their concerns about how they might die, what comfort care will be provided, and give their patients assurance that they will not be abandoned. The most important response to the PAS debate is to take every responsible measure to assure that all physicians are well trained in optimal end-of-life care and to remove all barriers to the delivery of such care.

PREAMBLE

their control. When nearing death, most people want empathic care that preserves their dignity. These wishes and fears have been well documented among cancer patients.

As the largest professional organization representing physicians who treat cancer, ASCO is committed to the highest standards of cancer care from diagnosis, cure, extension of quality of life, or death. Caring for the incurable patient means longitudinal involvement from diagnosis, administration of anticancer therapy, management of symptoms, management of recurrences, to death. It requires that physicians recognize an important turning point in a patient's course, when anticancer treatment strategies should give way to measures that have as their primary goal physical and emotional comfort and support. To achieve this end, it is essential to emphasize a humane system based on the following principles:

- Cancer care is centered around the longstanding, and continuous relationship between the primary oncologist and other physician with training and interest in end-of-life care, and the patient;
- Cancer care is responsive to the patient's wishes and to the parents' wishes if the patient is a child;
- Cancer care is based on truthful, sensitive, empathic communication with the patient, and in the case of pediatric patients, that care is both family centered as well as child focused; and
- Cancer care optimizes quality of life throughout the course of an illness through meticulous attention to the myriad physical, spiritual, and psychosocial needs of the patient and family.

The following statement was developed by the ASCO Task Force on Cancer Care at the End of Life. It represents a description of the principal role of the oncologist and an assessment of the barriers to optimal end-of-life care and proposed remedies.

I. ASCO Has Assessed Barriers and Proposes Remedies That Would Facilitate Provision of Optimal End-of-Life Care for Patients and Their Families.

A. Clinical Barriers and Their Remedies

Inappropriate attitudes of health care professionals and patients, ineffective communication about prognosis, unrealistic expectations and treatment options, and a failure of physicians to recognize and emphasize the importance of symptom management and psychosocial support in the care of dying patients:

There is a general consensus that many patients and physicians are reluctant to talk about death until dying is close at hand. Many physicians interpret disease progression and death as therapeutic failure rather than an outcome that is secondary to the limitations of available treatments or the anticipated outcome of the biology of disease. In the absence of clear, frank, and empathic discussions regarding prognosis, expected therapeutic outcomes, and management options, eg, palliative care in the appropriate clinical situation as opposed to anticancer treatment, there will be confusion about goals. Such confusion may lead the patient or family to erroneous assumptions concerning treatability or even curability. For instance, a patient

may interpret a 20% response rate as 20% cure rate, unless given explicit information. In turn, this may cause them to decline palliative care services until quite late in the illness, thereby diminishing the effectiveness of these efforts. This being the case, it is no surprise that physicians infrequently bring up the topic of advance directives, the need for a health care proxy in the event the patient cannot decide and communicate, and the therapeutic value of palliative care.

Societal attitudes may also be an impediment and should be addressed by physicians educating their patients and families, as well as broader public education efforts. Fear of opioid addiction may lead patients to underreport pain or underutilize prescribed analgesics. Misunderstanding the role of opioid analgesics at times causes patients to believe that their use is reserved for preterminal states; hence, their reluctance to truthfully discuss pain or be open to appropriate use of analgesics. If the physician does not inquire about pain at each encounter and offer assurance that addiction is not a clinical concern in this setting, patients will be discouraged from reporting all pain and using medication at sufficient doses to control discomfort. In addition, overzealous scrutiny of prescribing practices by regulatory bodies (or the perception thereof) may deter the physician from recommending use of these important analgesics in an optimal fashion.

Unrealistic expectations about the potential of modern medicine influence decision making. To the extent that the public assumes that technological approaches to cancer care will always prevail, it can be more difficult for both patient and doctor to embrace hospice/palliative care as a critical component of comprehensive cancer care.

Lack of Availability of Palliative Services and Fragmentation of Care

Access to physicians with expertise in symptom control and palliative care is erratic. In some communities, the agencies and services needed to provide quality end-of-life care are less well developed than in other locations. For example, palliative care teams are not available in all cancer centers, let alone within academic and community hospitals. In some centers, the appropriate expertise exists, but has not been organized into the type of integrated program that can be accessed by both outpatients and inpatients in a "user friendly" manner.

Physicians depend upon effective communication and team interactions with hospice or home health nurses or other home care professionals. Often multiple physicians are involved including the hospice medical director. In this context, fragmentation of care can occur and lead to ineffective control of symptoms. Although teamwork is crucial for end-of-life care in the home setting, it is vital that one individual, usually the oncologist or primary care physician, assume the role of team leader and the responsibility of coordinating the efforts of other team members. If unable to do so, it is incumbent to turn the leadership to a physician well trained in palliative care.

ASCO believes that provision of optimal end-of-life care requires access to and availability of state-of-the-art palliative care rendered by skilled clinicians, buttressed when necessary, by palliative care experts (see Appendix I).

The role of the oncologist and the care team is not simply to treat cancer, but to provide comprehensive palliative and anticancer therapy throughout the course of an illness. The principal physician responsible for the management of patients with cancer is the oncologist, who assumes this role at the time of diagnosis, and provides care through the course of therapy, recovery, or recurrence of cancer and death. This is a complex endeavor that requires diverse expertise and judgment, especially at that moment in the course of an illness when treatments directed at the cure of cancer are no longer likely to benefit the patient. At those moments, it is essential to modify the management goals and offer care that is directed at symptom management, and that is sensitive to a patient's spiritual and psychological needs. This usually requires that the oncologist, primary care physician, or hospice physician be well versed in the techniques of palliative care, including the control of physical and psychological symptoms, eg, control of nausea, anorexia, pain, diarrhea, constipation, fatigue, anxiety, and depression, and assume the role of team leader in coordinating the efforts of all other caregivers. These skills are essential for clinical effectiveness, but may exceed the expertise of any one physician. To buttress the support system, hospitals and cancer centers should have palliative care programs which incorporate nurses, pharmacists, psychologists, social workers, pastoral care providers, pain specialists, and ethicists; special expertise must be available for pediatric cancer patients and for the children of adult cancer patients. This team should be

coordinated by palliative care specialists and, whenever possible, provide consultation to assist other providers of care to terminally ill patients. Cancer specialists who are not comfortable or skilled at providing high-quality end-of-life care should make referrals to effective programs in their areas. Furthermore, it is incumbent upon them to make every effort to acquire these skills.

ASCO believes that hospice is a widely available and excellent model for managing end-of-life care and should be better utilized.

Hospice is the best developed model for end-of-life care in the US health care delivery system. Imported into this country in 1974 to provide for the unmet needs of dying patients and their families, hospice has not yet realized its full potential due to persistent underutilization and limited access. In 1996, 2,800 hospice programs provided hospice care to 450,000 patients in this country. Sixty percent of these patients died of cancer, accounting for 50% of cancer deaths that year, up from 33% in 1992. The average length of stay in a hospice program is approximately 2 months, with 15% dying within 2 weeks.

The National Hospice Organization (NHO) defines hospice as a comprehensive, medically directed, team-oriented program of care that seeks to treat and comfort terminally ill patients and their families at home or in a home-like setting, establishing pain management and symptom control as clinical goals, and understanding that psychological and spiritual suffering are as significant as physical pain. Hospice accepts death as a natural part of life and seeks to neither hasten nor prolong the dying process. Bereavement care is also available to the family following the death of the patient.

Hospice care is provided as part of the primary physician's continuing care of his or her terminally ill patient. Most hospice programs require that patients be willing and able to spend all or most of their terminal days at home, although the definition of home encompasses a board-and-care facility or a skilled nursing (convalescent) hospital. A caregiver usually becomes necessary to provide for daily needs and safety at home, although such a caregiver may be only intermittently available and hired.

Despite the excellent care that hospice has provided for the past 24 years in this country, it continues to be underutilized through nonreferral, late referral, and ineffective collaboration. Problems sometimes occur if the oncologist is not providing the home or hospice

care, since he or she often will lose direct "control" of the patient to the hospice physicians and nurses. Even if such a change in who directs medical management is in the best interest of the patient, it may be very difficult for both the oncologist and the patient to break off that very special relationship which has lasted for months or years. Nonetheless, late referrals compromise good end-of-life care and create economic obstacles that make it difficult for a hospice to sustain itself. Individualized palliative care requires time for the hospice team to assess the patient's needs and goals and to develop a trusting relationship with the patient and family. Since hospice programs receive per diem reimbursements, timely referral also allows the hospice to build up a reserve that can be used to support the more resource-intensive period that usually precedes death. 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.

B. Economic Barriers

The two key economic issues for patients and practitioners are lack of universal access to care and the severe underfunding of end-of-life care by the current care system. Inequities in economic access to care pose a major obstacle. Indigent patients, those who do not qualify for Medicaid, Medicare, or any insurance, can make up a substantial proportion of an oncology practice. These patients do not qualify for any specific end-of-life care programs and challenge the ingenuity of well-meaning practitioners whose resources for providing good end-of-life care are limited.

Access to hospice care is limited by administrative and fiscal constraints, cultural and social barriers. Medicaid and Medicare reimbursement for end-of-life care vary by state and by region, and some Medicaid programs do not cover hospice. Arbitrary limits on inpatient care reimbursement and restrictive capitation on total care reimbursement make it difficult for hospice programs to meet all the needs of referred patients. Patients requiring high-technology care for palliation of their disease or inpatient care because of the frailty of their social support system are often excluded from receiving hospice care. Already underfunded compared to similar services in the private sector, Medicaid and Medicare home care can expect service reductions. These affect the patients least likely to be able to afford supplemental insurance or out of pocket expenses.

Managed care plans and private insurance plans have evolved many different ways to handle end-of-life care benefits. Some have gone to a Medicare hospice-type program of true managed care. Others have simply expanded their home-care programs without a cancer focus. In the latter case, the experience of both the patient and the health care provider will depend greatly on the experience and expertise of the provider.

The cost of medications can be daunting. A 20% copayment on \$4,000 per month (as an example) for at-home continuous infusion morphine is substantial. Oral or transdermal pain medicine is not covered by many insurance companies and can easily cost hundreds of dollars a week. Assistance programs, such as the indigent care program administered by the Pharmaceutical Research and Manufacturers of America, have met with only limited success due to lack of awareness and limitation of the available resources.

It is essential that the economic barriers impeding access to optimal end-of-life care be removed. This includes making reimbursement for such care available to all Americans through insurance arrangements that do not vary from carrier to carrier. There must be appropriate support for hospice care and for home care that is rendered in a context other than hospice. Oral and/or transdermal analgesics must be covered by insurers without onerous copay arrangements.

From a societal perspective, end-of-life care is expensive no matter how it is done. About one third of Medicare dollars are spent on dying patients,¹ with no easy way to reduce that amount. The few studies that have examined comparative costs of end-of-life care have produced disparate results. One study commissioned by the NHO showed that Medicare saved money on patients who received hospice care, whereas several others failed to demonstrate an economic benefit to supportive care in the absence of disease-directed therapies. A number of studies have shown that end-of-life care is expensive, whether or not it includes palliative chemotherapy. It is essential not to trivialize the issue of cost in the health care system. However, society's emphasis must be on protecting those who are most economically and physically vulnerable. ASCO's emphasis must be on stimulating public policy that assures the accessibility and availability of technically expert and humane end-of-life care to

all Americans, independent of socioeconomic status or particular insurance arrangements. The existing system falls far short in this regard.

C. Educational Deficiencies as Barriers to Optimal Delivery of End-of-life Care

Physicians do not receive systematic education in the clinical and psychological aspects of caring for the terminally ill patient. Few courses emphasize this during the medical undergraduate years, and postdoctoral training programs are generally characterized by a “learning on the job” approach. Traditional apprenticeship-type learning is hampered by lack of role models with expertise at caring for the terminally ill. As a result, issues of paramount importance, such as pain and symptom management, learning how to discuss the realities of an illness with a patient and/or family in a way that conveys accurate information without removing hope, telling patients they are dying, telling patients what their death might be like, dealing with patient requests for assistance in dying, requesting organ donation, and requesting permission to perform an autopsy, are often never formally addressed. For those treating pediatric patients, this means telling parents their child is dying and what the death of their child might be like and telling children at an age-appropriate level that they are dying and what it might be like for them.

Barriers to developing optimal end-of-life teaching programs are complex and multifaceted. They include inappropriate attitudes about caring for the dying, blind insistence on the part of the physician and the patient/family on treating the disease, even in the absence of rational evidence, existential anxiety that is personal, but representative of a general reluctance on the part of society to deal with issues surrounding illness and death, and conflict between increasing time constraints for medical practice and ever-present service commitments. Where physicians treat scores of patients, there is little time to devote to learning from the dying, and little time to devote to teaching others. Physicians are trained to heal and/or cure disease by employing specific interventional therapies. Providing optimal end-of-life care requires acceptance that cure is sometimes not possible and that one can still be successful as a caretaker by tending to the physical, psychologic, and spiritual needs of a dying patient and his/her family.

ASCO believes that educational initiatives directed at optimizing the physician’s clinical and psychological skills in delivering end-of-life care are essential and must be directed at the medical student, pediatric and medical resident, oncology trainees from all disciplines, the practitioner, and allied members of the health care team.

ASCO can influence the training experiences of oncologists and those of practitioners. It has the responsibility to educate its members and to create an environment in which they can practice state-of-the-art cancer care throughout the entirety of each patient’s experience. Full integration of palliative care into the totality of cancer care mandates a shift in the current treatment paradigm. Oncologists must be trained to practice along the continuum of care and be held accountable for their practice. Accredited oncology training must include pain and symptom management, education in patient/family communication, medical ethics, and psychosocial support. The skills developed by trainees and experienced clinicians must be evaluated, rewarded as appropriate, and coupled with constructive feedback in order to determine if the physician has acquired the core values and skills to provide dying patients and their families with high-quality and compassionate care. Certifying boards should recognize and incorporate questions on exams that assess these skills.

ASCO argues for clear educational imperatives.

Acquiring effective communication skills. One of the best means of learning to communicate effectively in the terminal care setting is observational—being observed by experts and observing expert clinicians as they interact with patients at life’s end. Videos of expert clinicians interacting with real or simulated patients and standardized cases are also useful tools. Among the most effective ways of improving a trainee’s or practitioner’s level of performance is the physician role model. Physician faculty who are able to approach the care of the dying with technical expertise, humanism, patience, and good grace present the best opportunity of inculcating effective communication skills and positive attitudes in those whom they train. All doctors in training must be given opportunities to observe and work with mentors whose stature and skills in care at the end of life make their practice worth emulating.

Teaching palliative care. Courses, clinical clerkships, rotations during residency, and fellowship experiences must provide a sound didactic and practical experience in the numerous advances that have been made in symptom control. The team approach, in which trainees work closely with and observe physician role models, nurses, and other experts in a palliative care service or hospice setting, is an essential exposure that will foster learning and development of the necessary skills.

ASCO's programs, through symposia and workshops, will offer instruction in state-of-the-art clinical practice of end-of-life care, in-depth discussions of legal and ethical dilemmas, and will promote awareness of the economic barriers that impede optimal end-of-life care and how to overcome them.

II. ASCO Believes That There Is a Great Need for Research on the Physical, Psychological, and Socioeconomic Problems That Are Presented by the Terminal Phases of Illness.

Evidence based decision making is essential to assure a high standard of practice in clinical oncology. Unfortunately, there has been comparatively little research into the problems of care at the end-of-life. The two areas that have received the most attention relate to pain management and advanced care directives. Within the last few years, a few foundations have sponsored large, mostly descriptive studies on the care of terminally ill patients, such as the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a five-hospital study of treatments and decision-making for seriously ill patients, and the Commonwealth-Cummings Project. The consequence of this paucity of research is that the last major study on hospice care was conducted 15 years ago; there is no study quantitatively assessing the economic impact of terminal illness on families, few studies on symptoms other than pain, no studies evaluating the caregiving burdens and responsibilities of the families of terminally ill patients, and few studies defining predictors of poor or good outcomes and interventions that can ameliorate poor outcomes. In order to ensure that cancer patients receive high-quality and compassionate care at the end of life, we need significantly more research on outcomes, predictors, and interventions. It is imperative that the National Institutes of Health and philanthropic foundations develop programs that will sponsor research awards in this area.

ASCO believes that clinical decisions based on reliable evidence represent the most practical way to assure high-quality and compassionate end-of-life initiatives on outcomes, predictors and interventions during the end phase of terminal illness including:

Pain and other physical symptoms. Pain and pain management is one of the few end-of-life areas that has been the subject of substantial research. Much more needs to be done and there are several important areas still in need of further elucidation. These include research on effective interventions for neuropathic pain, visceral pain, and bone pain. In addition, research on barriers to providing better pain management is required. For instance, many oncologists claim that patient and family fears of addiction preclude the use of opioid analgesics. Some data on this would help in the design of interventions for physicians, patients, and families. Similarly, we lack understanding of the best mechanisms to educate physicians on appropriate pain management and hold them accountable for its delivery. Additional priorities include research on symptoms such as cachexia, asthenia, and chronic nausea. Furthermore, pulmonary abnormalities are common near the end of life and can produce extremely distressing symptomatology. We need to continue to explore the pharmacologic mechanisms underlying dyspnea, and identify new interventions directed at its relief.

Depression and other mental health symptoms. Psychological distress, including anxiety, depression, and suicide, have received little attention. Yet recent evidence suggests that these factors are important determinants of adverse outcomes among all patients, including terminally ill ones. A research commitment is needed to evaluate the mental health of patients at the end of life, identify predictors of depression and psychological distress, develop interventions that are appropriate for different types of distress, and establish optimal programs to improve oncologists' evaluation and treatment of patients with depression and psychological distress.

Spirituality and existential meaning. 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. This area has frequently been ignored because it seems outside the province of health care and not amenable to serious evaluation. Yet we have pastoral care providers working in hospitals, and hospices have routinely included pastoral care as part of their multidisciplinary meetings. Research on patients' existential and spiritual concerns, how they are addressed, what interventions might improve the concerns of patients, and whether such interventions improve overall end-of-life experience is needed.

Communication. One of the major areas long identified as important but still done poorly is communication about death and dying, both between physician and patient/parent and between patient and family. We are all afraid of talking about death and dying. We need significant research on methods to improve the education of doctors and of laypersons on communication about end-of-life care. Such research should include how to talk truthfully to cancer patients and their families about illness, treatment possibilities, prognosis, and advanced care planning without removing hope.

Caregiving burdens. Caring for patients at the end of life places an enormous burden on families and other caregivers. Little empirical data exist assessing burdens imposed on those who care for terminally ill patients, eg, predictors of high caregiving burden, home circumstances, as well as the effectiveness of various supportive interventions, such as home health aides and respite care in alleviating the burden.

Research has suggested that a patient's death can have serious adverse effects on family members, leading to increased rates of illness and even death. This emphasizes the importance of focusing on the larger social network affected by the death and dying of a patient. The information deficit on this issue is almost total. We have no predictors for adverse outcomes of family members. We do not know which caregivers and family members of terminally ill patients are most susceptible to illness and death. We do not know which interventions and at what times would be most effective in reducing these adverse outcomes. Research on grief and bereavement are needed to address the morbidity of the survivors.

Economic burdens. Research from the SUPPORT study has demonstrated that the dying process imposes enormous economic burdens on patients. Many patients and families lose income and spend down their assets to cover the cost of care. A thorough evaluation of these economic burdens, especially for predictors of high economic burdens, is still lacking. We also do not

understand what changes in insurance benefits or combination of services could reduce the economic burdens.

III. ASCO Believes That Physician-Assisted Suicide (PAS) Is a Complex and Subtle Issue Which Does Not Lend Itself to Formulaic Resolution, and for the Time Being Must Be Resolved on a Case by Case Basis Between the Patient and the Physician and Existing Law.

The ethos of medicine has long been interpreted as prohibiting any behavior on the part of a physician that would involve deliberately hastening a patient's death. During the past several decades, technological advances in the ability to sustain life have stimulated thoughtful debates between patients, doctors, clergy, and ethicists regarding the withholding of life-sustaining treatment or its withdrawal upon the direction of a competent patient or designated surrogate. Current ethical and legal opinions amply affirm that upon the request of a competent patient or patient surrogate, the physician is obligated to withdraw or withhold life-sustaining treatment, whether respirators and chemotherapy or antibiotics and blood transfusions. The recent Supreme Court decision supports the physician's intensive use of drugs to manage suffering.

A growing public debate has developed regarding the issue of PAS, a practice which typically involves a physician writing a prescription for lethal medication(s) to be voluntarily taken by a terminally ill patient with the intent to end his or her life. Although PAS and active voluntary euthanasia (the act of terminating a patient's life by direct drug administration) is tolerated but illegal in the Netherlands, euthanasia is illegal in the United States and most jurisdictions prohibit aiding another human being's suicide. The exception to this is Oregon, where PAS is now legal. Surveys point out that the concept of PAS is thought reasonable by a majority of people in this country. Physicians report being asked to help terminally ill patients end their own suffering, and among these are a small number of doctors who accede to this request.

The cacophony surrounding PAS obscures a number of fundamental considerations: (1) PAS is a most unusual event. While in the course of caring for a patient with a terminal illness, it is not uncommon for a patient to inquire about a physician's willingness to assure the patient's comfort at life's end. It is rare,

however, that an enduring request for assistance in dying is made; (2) a request for PAS may often emerge from the depths of a clinical depression or inadequate pain control, which therefore represents a failure to deliver optimal end-of-life care; (3) even in the presence of optimal end-of-life care, some patients' existential distress may not always be completely relieved; and (4) providing relief from intractable pain sometimes requires the use of sedation that may have the unintended effect of hastening death.

However, in many cases, the issues are subtle. Despite idealized treatment, a patient's suffering may continue, and that individual may request assistance in dying from his/her physician. The physician is urged to engage the patient in this uncomfortable discussion, and provide reassurance that the patient will not be abandoned. There are situations in which the request for PAS would seem justified to some caring physicians, and it is apparent that some doctors would accede to this request. It is equally apparent that some physicians believe PAS to be morally untenable under any circumstances. Furthermore, even if some physicians believed the request to be justified in any particular circumstance, many physicians would argue that the potential misuse or abuse of PAS as public policy is so great that it must remain illegal. The deliberations of this Task Force reflect this divergence of opinion. This is not the moment to endorse PAS as a matter of public policy, nor to condemn it. This is an opportunity to emphasize ASCO's core belief that:

The most important response to the public debate over PAS is to take every responsible measure to assure that all physicians are well trained in optimal end-of-life care, that the public be educated about their options for end-of-life care, and that all barriers to the delivery of optimal end-of-life care be removed.

CONCLUSION

ASCO recognizes the enormous challenges that lie ahead. The nation's health care system must be modified to assure unimpeded access to state-of-the-art end-of-life care, and the nation's clinical oncologists must be prepared to deliver the same for cancer patients. Our Society is uniquely poised to serve as a voice for the needs of our patients, and to assess the resources required by their physicians in order to meet these goals. This policy statement is designed to articulate the problem and identify opportunities for positive action. Achieving improvements in the quality of end-of-life care will require an ambitious program of professional education, new research initiatives, and strong advocacy efforts. Our resolve is to be as effective in caring for the needs of the 50% of our patients who are not cured by modern cancer therapies as we are in delivering the best in curative technology.

REFERENCE

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APPENDIX I
American Medical Association Institute for Ethics
Elements of Quality End-of-Life Care

The American Medical Association Institute for Ethics has released eight elements of quality end-of-life care. ASCO believes that these represent a high professional standard and cites them along with examples for their application to the care of patients with cancer.

Elements of Quality Care for Patients in the Last Phase of Life

Elements	Application to patients with cancer
1. The opportunity to discuss and plan end-of-life care.	The only way to address the issue of death is to directly bring it up. Patients should be asked how much they want to know about their illness and prognosis, and then given full information if desired. There are no data that full information either takes away hope or hastens death, and there are excellent resources for how to give bad news. Both doctors and patients may "burn out" with treatment and neglect these issues. Discussions on end-of-life care and planning, which should involve the family since they may be making decisions in the case of a patient's incompetence, can be done successfully in the office or hospital setting, within the current reimbursement structure. Patients should be offered the opportunity to make a living will or Durable Power of Attorney for Health Affairs while still mentally capable of making decisions.
2. Trustworthy assurance that physical and mental suffering will be carefully attended to and comfort measures intently secured.	Over 50% of hospital inpatients die with needless pain. The technology exists to relieve pain and other symptoms in nearly all of our patients, if we use it. Care of the dying cancer patient demands attention to symptom control, management of anxiety and depression, and may require consultation with appropriate palliative care specialists.
3. Trustworthy assurance that preferences for withholding or withdrawing life-sustaining intervention will be honored.	Nationwide, only about 20% of dying patients have advanced medical directives. Many physicians do not know the preferences of their dying patients. Knowing and following the preferences of our patients is part of our professional responsibility.
4. Trustworthy assurance that there will be no abandonment by the physician.	Sometimes patients will continue with active therapy in the mistaken belief that they will be abandoned if they switch to palliative therapy. In reality, visits are often scheduled around the giving of chemotherapy. Telling patients that one is switching to active management of symptoms rather than active treatment of the cancer because anticancer treatment has not worked, and that you will not abandon the patient, may assuage some of these fears.
5. Trustworthy assurance that dignity will be a priority.	This assurance should be a concern from the very outset of caring for cancer patients, not just when aggressive care is ended. This may be especially important to patients with a long history of independence, and new found progressive losses of mobility, self care, and activities of daily living. Directly ask the patient/parents if there are problems with activities of daily living.
6. Trustworthy assurance that burden to family and others will be minimized.	Patients can be referred to hospice or palliative care services if the physician office is not set to offer such assistance. The National Cancer Institute Cancer Information Service, 1-800-4CANCER, or the National Hospice Organization, 1-800-658-8898, can provide a list of available local hospices and services.
7. Attention to the personal goals of the dying process.	Most patients will have some personal goals to complete such as family communications or legacies, a last trip, etc. In addition, 70% of patients prefer to die at home, yet less than 20% actually do. The only way to determine preference for place of death is to ask, and then to plan for it.
8. Trustworthy assurance that caregivers will assist the bereaved through the early stages of mourning and adjustment.	Pathologic grief must be diagnosed and referred to psychosocial counselors, and such care is provided by hospice programs. Physicians and other caregivers should make it part of optimal care to express their condolences to the families of their deceased patients.

APPENDIX II
Task Force on Cancer Care at the End of Life

Member	Institution
Lowell E. Schnipper, MD, Chair	Beth Israel Hospital, Boston, MA
Jacob D. Bitran, MD	Lutheran General Hospital, Park Ridge, IL
Linda L. Blank	American Board of Internal Medicine, Philadelphia, PA
Diane Blum, MSW	Cancer Care, Inc., New York, NY
Dan Brock, PhD	Brown University, Providence, RI
Eduardo Bruera, MD	Grey Nuns Community Health Center, Edmonton, Canada
Ezekiel J. Emanuel, MD, PhD	National Institutes of Health, Bethesda, MD
Kathleen M. Foley, MD	Memorial Sloan-Kettering Cancer Center, New York, NY
David S. Gordon, MD	Aronex Pharmaceuticals, The Woodlands, TX
Joanne M. Hilden, MD	Children's Health Care, St. Paul, MN
Robert A. Kagan, MD	South California Kaiser Permanente Radiation Oncology, Los Angeles, CA
Michael H. Levy, MD, PhD	Fox Chase Cancer Center, Philadelphia, PA
Allen S. Lichter, MD	University of Michigan Medical Center, Ann Arbor, MI
Michael P. Link, MD	Stanford University, Palo Alto, CA
W. Charles Penley, MD	The Consultant Group, Nashville, TN
Thomas J. Smith, MD	Massey Cancer Center, Medical College of Virginia, Richmond, VA
Karen Stanley, RN, MSN, AOCN	Kaiser Permanente, Fontana, CA
Ellen Stovall	National Coalition for Cancer Survivorship, Silver Spring, MD
Laurence Kevin Tokaz, MD	Texas Oncology, P.A., Austin, TX
William C. Wood, MD	Emory University School of Medicine, Atlanta, GA
Robert Mayer, MD (Ex-Officio)	Dana-Farber Cancer Institute, Boston, MA