Seven Legal Barriers to End-of-Life Care: Myths, Realities, and Grains of Truth

Alan Meisel; Lois Snyder; Timothy Quill; et al.

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Seven Legal Barriers to End-of-Life Care
Myths, Realities, and Grains of Truth

Alan Meisel, JD
Lois Snyder, JD
Timothy Quill, MD
for the American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus Panel

Objective The American College of Physicians-American Society of Internal Medicine (ACP-ASIM) End-of-Life Care Consensus Panel was convened in 1997 to identify clinical, ethical, and policy problems in end-of-life care, to analyze critically the available evidence and guidelines, and to offer consensus recommendations on how to improve care of the dying. Topic selection and content presentation were carefully debated to maximize the project's focus on providing practical clinical and other guidance to clinicians who are not specialists in palliative care. This statement examines current legal myths, realities, and grains of truth in end-of-life care.

Participants The Consensus Panel comprises 13 medical and bioethics experts, clinicians, and educators in care at the end of life selected by the Ethics and Human Rights Committee, College leadership, and the Center for Ethics and Professionalism at the ACP-ASIM.

Evidence A literature review including a MEDLINE search of articles from 1970-1998 and review of end-of-life care literature and organizational bibliographies was conducted. Unpublished sources were also identified by participants, as was anecdotal clinical experience.

Consensus Process The draft statement was debated by panel members over a series of 3 to 4 meetings. For this statement, the initial draft and subsequent revised drafts were discussed in 1998-1999. The statement then underwent external peer review and revision before panel approval and the journal peer review process.

Conclusions Legal myths about end-of-life care can undermine good care and ethical medical practice. In addition, at times ethics, clinical judgment, and the law conflict. Patients (or families) and physicians can find themselves considering clinical actions that are ethically appropriate, but raise legal concerns. The 7 major legal myths regarding end-of-life care are: (1) forgoing life-sustaining treatment for patients without decision-making capacity requires evidence that this was the patient's actual wish; (2) withholding or withdrawing of artificial fluids and nutrition from terminally ill or permanently unconscious patients is illegal; (3) risk management personnel must be consulted before life-sustaining medical treatment may be terminated; (4) advance directives must comply with specific forms, are not transferable between states, and govern all future treatment decisions; oral advance directives are unenforceable; (5) if a physician prescribes or administers high doses of medication to relieve pain or other discomfort in a terminally ill patient, resulting in death, he/she will be criminally prosecuted; (6) when a terminally ill patient's suffering is overwhelming despite palliative care, and he/she requests a hastened death, there are no legally permissible options to ease suffering; and (7) the 1997 Supreme Court decisions outlawed physician-assisted suicide. Many legal barriers to end-of-life care are more mythical than real, but sometimes there is a grain of truth. Physicians must know the law of the state in which they practice.

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APRIL 15, 2000, MARKED THE 25th anniversary of the start of the Karen Ann Quinlan case and, with it, the initiation of much of the public discussion concerning end-of-life medical treatment. Substantial legal, ethical, and clinical consensus currently exists about end-of-life care,[1,2] yet myths and misconceptions persist about what is ethically and legally permissible.[3] Also, at times ethics, clinical judgment, and the law conflict. Patients (or families) and physicians find themselves considering clinical actions that are ethically and morally appropriate, but raise legal concerns.

The legal context in which care is provided influences both interventions and outcomes. Liability is on the minds of physicians, who tend to overestimate the risk of malpractice lawsuits.[4] For instance, in a survey of emergency department physicians, most said legal concerns should not affect resuscitation practices (78%), but they do (94%).[5] Communication by physicians about end-of-life care issues is a primary concern to families of terminally ill patients[6,7] and is often found to be inadequate,[8,9] a factor associated with increased risk of lawsuits.[10,11]

Legal myths about end-of-life care can lead to actions that comport neither with legal or ethical norms, nor with the norms of good medical practice. TABLE 1 summarizes current legal myths and realities discussed in this article. TABLE 2

Author Affiliations: Center for Medical Ethics, University of Pittsburgh School of Law, Pittsburgh, Pa (Mr Meisel); Center for Ethics and Professionalism, American College of Physicians-American Society of Internal Medicine, Philadelphia, Pa (Ms Snyder); and Department of Medicine, Genesee Hospital, Rochester, NY (Dr Quill).

A list of the members of the American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus Panel appears at the end of this article.

Corresponding Author and Reprints: Lois Snyder, JD, Center for Ethics and Professionalism, American College of Physicians-American Society of Internal Medicine, 190 N Independence Mall W, Philadelphia, PA 19106 (e-mail: lsnyder@mail.acponline.org).

Health Law and Ethics Section Editors: Lawrence O. Gostin, JD, the Georgetown/Johns Hopkins University Program in Law and Public Health, Washington, DC, and Baltimore, Md; Helene M. Cole, MD, Contributing Editor, *JAMA*.

summarizes the current status of legal myths prevalent in 1991.[12] Some of those myths have now diminished in importance, others persist, and new ones have emerged, creating ongoing barriers to appropriate end-of-life care. One reason for the new myths is that the scope of the debate about the boundaries of end-of-life care has expanded substantially since the *Quinlan* case,[13] including discussion about aggressive management of pain and other symptoms and the possibility of actively hastening death as a last resort.

We will outline some of the current myths, realities, and grains of truth in several domains of end-of-life care. Physicians should be aware that state laws and hospital protocols affecting end-of-life care vary, and should seek legal counsel when needed in particular clinical situations.

WITHHOLDING AND WITHDRAWING TREATMENT

Myth 1: Forgoing Life-Sustaining Treatment for Patients Without Decision-Making Capacity Requires That There Be Evidence That This Was the Patient's Actual Wish

The reality is that life-sustaining treatment for patients without decision-making capacity may be forgone if the patient's surrogate relates that this was the patient's actual wish, or, in most states, if it was only the patient's probable wish. In a small number of states, under certain circumstances it is even permissible to terminate life support with the surrogate's permission if the patient's wishes are not known, if termination of treatment is in the patient's "best interests."[14]

Confusion about this issue may result from the Nancy Cruzan case in Missouri in which the US Supreme Court held that physicians were not obligated to terminate treatment at the family's request but could insist on "clear and convincing evidence" that this was the patient's actual wish. However, the Court did not require that other states adopt this standard,[15] which in practice is difficult to meet—and most states have not done so. Rather, the prevalent position in law, ethics, and medical practice is to apply the "substituted judgment standard" under which family members are permitted to make end-of-life decisions on the basis of the patient's probable wishes. Most courts presume that family members will know best whether the patient would want to forgo treatment.

The best evidence of a patient's wishes about life-sustaining treatment is an advance directive. Yet despite the Patient Self-Determination Act and widespread ethical and legal support for advance directives, less than one fifth of patients complete one.[16] Physicians should encourage competent patients to write living wills and/or make surrogate designations through use of a durable power of attorney for health care. When these measures have not been taken by patients, the default approach common in clinical practice is to go to the closest family members to represent the patient in clinical decision making when the patient cannot speak for himself/herself. This default procedure has been codified in law in about two thirds of states.[14,17] Even in some states without these laws, courts have concluded that close family members may authorize the termination of life support of an incompetent patient.[14]

End-of-life decision making when the patient cannot speak for himself/herself, however, is often not simple. Sometimes a family member's (and/or a close other's) views about care conflict, or there is conflict between fam-

Table 1. Current Legal Myths and Realities

Myth	Reality
Forgoing life-sustaining treatment for patients without decision-making capacity requires evidence that this was patient's actual wish.	Such treatment may be forgone if the patient's surrogate relates that this was the patient's actual wish or, in most states, if it was the patient's probable wish. Only a few states require "clear and convincing" evidence of patient wishes. In a few states, it is even permissible to terminate life support with the surrogate's permission if the patient's wishes are not known, if termination of treatment is in the patient's "best interests."
Withholding or withdrawing of artificial fluids and nutrition from terminally ill or permanently unconscious patients is illegal.	Like any other medical treatment, fluids and nutrition may be withheld or withdrawn if the patient refuses them or, in the case of an incapacitated patient, if the appropriate surrogate decision-making standard is met.
Risk management personnel must be consulted before life-sustaining medical treatment may be terminated.	There is no legal requirement that a risk manager be consulted before making end-of-life decisions though some hospital policies may require it.
Advance directives must comply with specific forms, are not transferable between states, and govern all future treatment decisions. Oral advance directives are unenforceable.	Advance directives, often the best indication of an incapacitated patient's wishes, may guide end-of-life decision making even if all legal formalities are not met. A living will or surrogate should not be consulted if the patient retains decision-making capacity unless expressly authorized by the patient. Oral statements previously made by the patient can also be legally valid advance directives.
If a physician prescribes or administers high doses of medication to relieve pain or other discomfort in a terminally ill patient, resulting in death, he/she will be criminally prosecuted.	If a patient inadvertently dies from the use of high doses of medication intended to treat pain, the physician has not committed murder or assisted suicide.
When a terminally ill patient's suffering is overwhelming despite palliative care, and he/she requests a hastened death, there are no legally permissible options to ease suffering.	Although physician-assisted suicide is illegal in most states, terminal sedation is a legal option to treat otherwise intractable symptoms in the imminently dying.
The 1997 Supreme Court decisions outlawed physician-assisted suicide.	Physician-assisted suicide is currently legal in Oregon. Other states are free to legalize or prohibit it.

ily members' views and what is known of the patient's wishes. This can be challenging for clinicians in trying to provide the best care, and can create fear of litigation. Decision making for patients who are incapacitated but not permanently unconscious, such as those with Alzheimer disease, sometimes raises additional challenges.[18]

Grains of Truth. New York law does require evidence of an incapacitated patient's actual wish to forego treatment and under some circumstances, so do Missouri, Michigan, and Wisconsin.[19-21]

In states that follow this restrictive requirement, there can be variation among hospitals. At one extreme, the ethically sound decisions of caring families may be overridden by health care professionals for their own legal protection. At the other extreme, families may be coached to remember conversations that may or may not have taken place with the patient about treatment preferences, undermining the integrity of the process and increasing the risk of family problems with bereavement.

If there are differences in family opinion about how to proceed, the wishes of a family member advocating a more aggressive medical approach are likely to be given greater weight, even if not based on evidence about patient preferences. This is because of the perceived belief that the legal risks of continuing treatment are less than those of stopping it. The default in favor of aggressive treatment is probably stronger if the patient lacks capacity but is not permanently unconscious and has been unclear about his/her wishes.

Myth 2: Withholding or Withdrawing of Artificial Fluids and Nutrition From Terminally Ill or Permanently Unconscious Patients Is Illegal

The reality is that fluids and nutrition are like any other medical treatment, and therefore a physician may withhold or withdraw them if the patient refuses this treatment or, in the case of an incapacitated patient, the appropriate standard (as described in Myth 1) is met.

Since 1983, numerous state courts have given their approval to the withholding or withdrawal of artificial nutrition and hydration to terminally ill and permanently unconscious patients, if authorized by the patient in an advance directive, or by a close family member or other legally authorized person.[14] In these cases, the death of the patient results from the patient's underlying condition rather than from the conduct of the person who withholds or withdraws the nutrition and hydration, so there is no legal liability for the patient's death. The Supreme Court's 1990 *Cruzan* decision[15] gave qualified approval to this practice.

Grains of Truth. States with high legal standards about withholding and/or withdrawing feeding tubes or other life-sustaining therapy may effectively preclude these options from being legally available to patients who have not explicitly refused the particular treatment in question in advance of losing decision-making capacity. Even in states that do not generally require evidence of the patient's actual wishes, nursing homes are often reluctant to permit the withholding or withdrawing of artificial feeding without an explicit statement in a written living will, for fear of being the target of regulatory investigation.[22]

Myth 3: Risk Management Personnel Must Be Consulted Before Life-Sustaining Medical Treatment May Be Terminated

The reality is that there is no legal requirement that a risk manager be consulted before making end-of-life decisions, though some hospital policies may require it. The objective of risk management is to minimize legal risk to the institution, and not necessarily to advise what is ethically or clinically appropriate for a particular patient, or even to provide an objective legal analysis of the particular situation. Thus, ad-

Table 2. Status of Previously Identified Legal Myths

Myth	Current Status
There must be a law authorizing the termination of life support.	Currently existing law supports the termination of life support in all 50 states for both competent patients and for those who have lost capacity if there is consensus among those who care about the patient that it would be the patient's will or in his/her best interests.
Termination of life support is murder, assisted suicide, or suicide.	Termination of life supports is considered to be freeing the patient from unwanted bodily invasion. Death is legally considered to be a result of the patient's underlying disease. The law clearly distinguishes such acts from suicide, assisted suicide, or euthanasia.
A patient must be terminally ill for life support to be stopped.	The law allows any patient to refuse any treatment that he/she does not want, in the interest of protecting bodily integrity, even if that treatment would be life sustaining and the patient is not terminally ill.
It is permissible to terminate extraordinary treatments, but not ordinary ones.	The distinction between ordinary and extraordinary treatments is not relevant as a matter of law or ethics. The patient has the right to terminate any treatment, potentially life sustaining or not.
It is permissible to withhold treatment, but once started, it must be continued.	Although many clinicians think and feel differently about these types of actions, the law and medical ethics treat the withholding and the cessation of life-sustaining treatment the same.
Stopping artificial nutrition and hydration is legally different from stopping other treatments.	In most states, artificial hydration and nutrition are considered medical treatments like any other.*
Termination of life support requires going to court.	The courts generally want clinicians to make these decisions without going to court, provided there is a consensus among those who care about the patient about how to proceed.*
Living wills are not legal.	Living wills have legal support in all 50 states, either through legislation or case law.*

*See "Myth 2" section for further explanation.

vice from risk managers will not necessarily yield a desirable clinical, ethical, or legal result.

When end-of-life care treatment dilemmas loom, consultation with an ethics committee or an ethics consultant can be helpful. However, in some health care institutions, risk managers may have significant influence on the advice given in an ethics consultation, especially when there is some legal uncertainty, and they tend to err on the side of overestimating the risk to the institution of allowing the termination of life support.[23] Thus, it is useful for physicians to be aware of the law in their state as it applies to end-of-life decisions when considering what is clinically and ethically appropriate for their patients and to be able to evaluate advice given by risk managers and in ethics consultations.

Grains of Truth. Even though there is no legal requirement to consult a risk manager, individual hospitals may have adopted such a requirement through internal procedures. A risk manager may give greater weight to the hospital's legal protection than to the ethical, medical, and legal interests of the patient when there is legal uncertainty.

ADVANCE DIRECTIVES

Myth 4: Advance Directives Must Comply With Specific Forms, Are Not Transferable Between States, and, Once Signed, Govern All of a Patient's Future Treatment Decisions; Oral Advance Directives Are Unenforceable

The reality is that advance directives are frequently the best source of information about an incapacitated patient's wishes, and therefore should provide guidance in end-of-life decision making even if they do not comply with all legal formalities.

The myth that advance directives are not legally valid has virtually disappeared in the face of the enactment of authorizing legislation in virtually all states. All have health care power of attorney statutes. All but 3 have living will statutes, and in those 3 states (Massachusetts, Michigan, and New York) there are court decisions recognizing their validity.[19,24,25]

Many advance directive statutes contain living will or health care power of attorney forms. Health care professionals (and even their legal counsel) sometimes believe that to be valid, an advance directive must use this form. Although there are some advantages to doing so, a living will or health care power of attorney that does not strictly follow the statutory form is also valid in most states.

Another misconception about advance directives is that they are not portable, which would mean that they are not enforceable except in the state in which they were executed. Many, but not all, advance directive statutes contain provisions making valid advance directives from other states enforceable in the state in which the patient now resides. But even without such a provision, an out-of-state advance directive, like an oral statement or a nonstate form advance directive, still provides the best evidence of the patient's treatment wishes or choice of surrogate decision maker.

The purpose of advance directives, acknowledged in most advance directive statutes, is to guide decision making after a patient has lost decision-making capacity. Thus, as long as a patient retains decision-making capacity, a living will or the patient's surrogate decision maker should not be consulted about the patient's health care decisions unless the patient expressly authorizes it.

Oral advance directives, made by the patient about treatment preferences or designating a health care surrogate before losing the capacity to decide, are also legally valid.[14] These statements should be documented in the patient's medical record. Often, conversations with patients before or during a final illness can be more useful in determining the patient's treatment wishes or choice of surrogate decision maker than a living will.

Grains of Truth. Using an official form does have some advantages over other written documents or physicians' notes. The state form, if available, carries with it the perception that it is valid, and thus it may be more likely to be implemented, especially if the patient's regular physician is not among those caring for the patient.

There can be difficulties in proving that oral statements were made and what the specific terms were, especially if there is disagreement among family members. Written advance directives may be more likely to be honored especially if the patient's regular physician, who may know the patient's wishes and be able to give credibility to the family's reports of the patient's wishes, is not involved in the patient's care.

PAIN MANAGEMENT AND LAST RESORTS

Myth 5: If a Physician Prescribes or Administers High Doses of Medication to Relieve Pain or Other Discomfort in a Terminally Ill Patient and This Results in Death, the Physician Will Be Criminally Prosecuted

The reality is that if a patient inadvertently dies from the use of high doses of medication intended to treat pain,[26] the physician has not committed murder or assisted suicide.

In 1997, the US Supreme Court ruled on the constitutionality of laws making physician-assisted suicide a crime[27,28] and several justices wrote about medications for pain relief. Some opinions supported the use of pain relief medications even in doses that could hasten death, as long as the physician's intent in administering them is to relieve pain and suffering and not to end the patient's life.

The opinions have been hailed by some as creating a constitutional right to excellent pain management and/or to palliative care.[29] Even if the opinions do not go that far, they do clarify some uncertainties that have long plagued end-of-life decision making. The first concerns the doctrine of double effect. Physicians have long been concerned that because the medications needed to provide adequate pain relief to terminally ill patients carry a risk of indirectly and accidentally ending the patient's life by de-

pressing the patient's respiration, this will subject the physician to possible criminal prosecution and other legal sanctions. Though generally overstated and overestimated compared with clinical reality,[30] this small risk likely contributes to clinicians' reluctance to use of opioids and to the undertreatment of pain in general.

The traditional response has been that the doctrine of double effect should alleviate these concerns. Applied in these circumstances, the doctrine holds that when an intervention is used for a legitimate purpose (eg, pain relief) but has an unintended effect that would be illegitimate if it were intended (eg, death of the patient), the physician is not morally responsible for the unintended effect.[31]

While this moral doctrine might have eased physicians' consciences, it should not necessarily have eased their concerns about legal responsibility for the patient's death. Prior to the Supreme Court's decisions, in most states there was no secure legal basis for believing that the doctrine of double effect would contribute to a valid legal defense if a terminally ill patient inadvertently died due to the effects of analgesic, sedative, or anxiolytic medications, even if these medications were necessary to treat the patient's condition. Although the Supreme Court's decisions do not provide an airtight legal defense when death accidentally occurs from such medications, they give greater assurance that physicians will not be legally responsible under such circumstances. In addition to the protection afforded by the Supreme Court's opinions, almost half the states have adopted legislation recognizing a right to adequate palliative care[14,32,33] that confer varying kinds and degrees of legal protections on physicians.[34]

Grains of Truth. The application of double effect is ambiguous particularly if rapidly accelerating doses are needed to treat a terminal crescendo of pain,[35] and the line between intending to actively hasten death and intending to relieve pain and suffering can be hazy. A physician who intends to actively hasten death may be able to escape legal sanctions by claiming an intent merely to treat pain. On the other hand, the physician who intends to relieve pain and suffering could face legal sanctions if it is difficult to prove this intent. It is impossible to eliminate entirely the risk of potential prosecution for assisted suicide or even homicide, tort liability for wrongful death, disciplinary action by state licensing authorities, or investigation by the federal Drug Enforcement Administration or similar state authorities. Although physicians acting in accordance with good medical practice have a strong defense, such investigations can take an enormous psychological and/or financial toll on a clinician's personal and professional life.

While palliative care legislation may be an important step in the direction of improving access to adequate pain management and providing protection for physicians prescribing in good faith, these statutes have a number of flaws,[36] including the fact that they do not provide complete immunity from liability, and that half the states have not adopted them.

The safest legal course—based on a comparison of the current legal risks of underprescribing with the risks of prescribing large doses of opioids frequently needed for intractable pain—may still be to underprescribe, though it is the most morally suspect. However, the risk of malpractice suits and disciplinary action for underprescribing pain medications in the face of intractable pain may be on the increase, which might provide some legal counterbalance for the small risk of being accused of overprescribing.[37]

Myth 6: When a Terminally Ill Patient's Suffering Is Overwhelming Despite Excellent Palliative Care and the Patient Is Requesting a Hastened Death, There Are No Legally Permissible Options to Ease Suffering

The reality is that although physician-assisted suicide is illegal in most states, terminal sedation may be a legal option to treat otherwise intractable symptoms in the imminently dying.

Although refusing to declare state bans on assisted suicide unconstitutional, the Supreme Court gave indications of approval of "terminal sedation" with the informed consent of the patient.[28,38] Terminal sedation integrates 2 legally accepted clinical practices: (1) sedation of the patient to unconsciousness or a level that ensures escape from intolerable suffering, and (2) withholding life-sustaining therapy including food and fluids.[39-41] Even if sedation risks accelerating death, it is consistent with the doctrine of double effect as long as its primary purpose is to ease the patient's pain, discomfort, and anxiety. (In fact, not only is it legally permissible for physicians to provide sedation during the termination of life support to avoid any pain, discomfort, or anxiety, there is even some legal precedent for the view that sedation must be provided under these circumstances.[42-44]) The legal and clinical acceptability of withholding of fluids and nutrition was discussed in Myth 2.

Grains of Truth. Although the Supreme Court approved terminal sedation, and each of its 2 components is legally acceptable, the combination of the 2 components has never been tested in the courts, and thus its overall legality is somewhat uncertain. There is some debate about whether such practice represents "slow euthanasia"[45] or is simply a combination of standard palliative practices. In legal application, the biggest stumbling block is the physician's intention: whether it is the relief of suffering (legal) or the active hastening of death (illegal).

Clinical, ethical, and legal discussions about terminal sedation are relatively undeveloped compared with other end-of-life practices, and practice guidance has been proposed,[39] but not endorsed by professional organizations, so terminal sedation is likely to be unevenly available.

Myth 7: The 1997 Supreme Court Decisions Outlawed Physician-Assisted Suicide

The reality is that physician-assisted suicide is currently legal in Oregon and

other states are free to legalize or prohibit it.

In the 1997 US Supreme Court cases, terminally ill patients and their physicians in Washington State and in New York State argued that the laws of these states that make aiding suicide a crime were unconstitutional, at least when the adult seeking to end his/her life is competent and terminally ill and when the person providing the assistance is a licensed physician. These challenges failed, with the Supreme Court ruling that laws making aiding suicide a crime do not violate the US Constitution, and thus there is no constitutional right to physician-assisted suicide.

However, the Supreme Court did not rule that states cannot legalize physician-assisted suicide. Thus, although the US Constitution does not require states to legalize physician-assisted suicide, the Court left to each state how to address the legalization and concerns over physician-assisted suicide.

In 1994, Oregon voters approved such a law by referendum. This law, the Oregon Death with Dignity Act,[46] permits a physician to prescribe a lethal dose of medication, which the patient must self-administer, for a competent, terminally ill person who requests it. Four months after the US Supreme Court declined to recognize a constitutional right to physician-assisted suicide, the Court also refused to block implementation of this law.[47] About 2 weeks later, Oregon voters reaffirmed their support for the legalization of physician-assisted suicide by a margin of 60% to 40%.

Since the Oregon law allows a physician to write a prescription for, but not to administer, a lethal substance, the law clearly distinguishes this practice from euthanasia, in which the physician would administer the lethal medication at the patient's request. Physicians openly practicing euthanasia are more likely to be vigorously and successfully prosecuted,[48] as exemplified by the successful prosecution of Jack Kevorkian, for administering a lethal injection to a patient, after several unsuccessful prosecutions for aiding patients in ending their own lives.

Because physician-assisted suicide has been legalized only in Oregon, physicians in other states who provide a patient with the means to end his/her own life, knowing that the patient intends to do so, could be subject to criminal prosecution and the imposition of professional discipline. In practice, however, it is an open secret that such conduct sometimes occurs without the imposition of any legal sanctions.[49-51]

It is not legally permissible in any state for a physician to administer a substance to a patient with the intent to end the patient's life, even at the patient's request or with the patient's consent. However, if the physician's intent is the relief of pain and suffering, and the patient dies as an unintended consequence, there should be no criminal liability under the principle of double effect.

Grains of Truth. Despite the Supreme Court's ruling that states are free to legalize physician-assisted suicide, only Oregon has done so. Furthermore, several states that previously had no statute making assisted suicide a crime have subsequently criminalized the practice.

CONCLUSION

While there is much legal and ethical consensus about care of the dying, some confusion and gray areas remain. Some legal barriers are more mythical than real, but many times there is a grain (or more) of truth in the myth, which is probably 1 reason that physicians may overestimate the legal risks of some practices. In addition, departures from the consensus exist in individual states, and thus physicians must know the law of the state in which they practice.

Members of the American College of Physicians-American Society of Internal Medicine (ACP-ASIM) End-of-Life Care Consensus Panel: Bernard Lo, MD, FACP, chair, University of California, San Francisco; Janet Abrahm, MD, FACP, and Paul Lanken, MD, FACP, University of Pennsylvania, Philadelphia; Susan Block, MD, Dana Farber Cancer Institute, Boston, Mass; William Breitbart, MD, Memorial Sloan-Kettering Cancer Center, New York, NY; Ira Byock, MD, Palliative Care Services, Missoula, Mont; Kathy Faber-Langendoen, MD, State University of New York Health Science Center, Syracuse; Lloyd W. Kitchens, Jr, MD, FACP, Texas Oncology, Dallas; Joanne Lynn, MD, FACP, Center to Improve Care of the Dying, Washington, DC; Diane Meier, MD, FACP, Mount Sinai School of Medicine, New York, NY; Timothy E. Quill, MD, FACP, The Genesee Hospital, Rochester, NY; George Thibault, MD, FACP, Partners Healthcare System, Boston, Mass; and James Tulsky, MD, VA Medical Center, Durham, NC. Primary staff to the panel: Lois Snyder, JD, project director, ACP-ASIM, Philadelphia; and Jason Karlawish, MD, clinical staff, University of Pennsylvania, Philadelphia.

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Death,
The undiscover'd country from whose bourn
No traveler returns . . .

—William Shakespeare (1564-1616)