



## End-of-Life Decision Making

### **End-of-Life Decision Making**

(Adopted 1997 and reaffirmed 2004)

#### **Introduction**

*“A dying man needs to die, as a sleepy man needs to sleep, and there comes a time when it is wrong, as well as useless, to resist.”*

*Stewart Alsop*

- (1) Life is a continuum framed by the mysteries of birth and death. As medical science has advanced, it has succeeded in modifying events at both ends of the continuum, but death remains inevitable. Despite clinical interventions -- and sometimes because of them -- society and health care professionals face a tangle of dilemmas at the end of life.
- (2) Physician assistants are students and practitioners of the science of life. Death is an integral part of each life, making end-of-life problems an appropriate subject of serious study for PAs. The growth of medical technology and knowledge has increasingly blurred the line between life and death. Many advances are double-edged: techniques that rescue one person from premature and needless death can cause suffering, indignity, and financial ruin for another person whose death is inevitable.
- (3) Every death takes place in a unique set of circumstances. These include the clinical aspects of disease; the ethical and religious beliefs of the patient and caregivers; physical and emotional tolerance of pain; and the availability and acceptability of measures to prolong life and/or reduce suffering.
- (4) Although ethical and moral principles are often considered absolute and unchanging, they are actually dynamic and evolving, defined largely by society. From one generation to the next, changes in knowledge, values, and social structure have resulted in substantial shifts in the limits of what is morally and ethically acceptable regarding death and many other subjects.

#### **Historical Background**

- (5) For thousands of years, many nomadic peoples practiced active euthanasia when elders could no longer function independently or keep up with the tribe. In ancient Greece, assisted suicide was officially sanctioned: "Whoever no longer wishes to live shall state his reasons to the Senate. If your existence is hateful to you...abandon life." (Libanius) Japanese culture long considered suicide an acceptable option to escape dishonor or advance military goals.
- (6) During the Renaissance, scientific enlightenment merged with Christian philosophy and a more stable social structure to form the basis of many modern Western views on ethics and morality. In Thomas More's *Utopia*, "the Utopians treat the sick with great kindness and leave nothing undone to restore their health...but if a disease is not merely beyond

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treatment, but is also a constant source of pain and agony, the priests and magistrates remind him that he is not up to all the tasks of life, is troublesome to others and a burden to himself, and is now outliving his own death."

- (7) In modern times, end-of-life quandaries have been fueled by the explosion of clinical advances enabling the postponement of death, indefinitely in many cases. The use of mechanical ventilators to assist breathing began a mere four decades ago. Then came defibrillators, hemodialysis, cardiopulmonary resuscitation, pacemakers, heart-lung bypass, and ventricular assist devices, not to mention vast progress in pharmacologic life support and parenteral nutrition.
- (8) As technology boomed, medical decision making shifted away from physicians, whose primacy had been unchallenged for centuries. A more informed, consumer-minded, and anti-authoritarian public began to demand a greater role in making decisions about their own medical care.<sup>1</sup> Here are some milestones in the evolution of this debate:
- (9) Euthanasia, while still technically illegal, becomes socially and politically acceptable under certain circumstances in the Netherlands in the early 1970s.<sup>2</sup>
- (10) *On Death and Dying*, by Elizabeth Kubler-Ross, published in 1969, brings the process of death into the realm of popular discussion.<sup>3</sup>
- (11) In 1974, the first hospice in the US is founded by Hospice Inc., in New Haven, CT.
- (12) The parents of Karen Ann Quinlan, a young woman in a "persistent vegetative state," petition to have their daughter removed from artificial life support. The request is granted on appeal in 1976. Quinlan lives for several years after life support is withdrawn.<sup>4</sup>
- (13) California passes its "Natural Death Act" in 1976, allowing competent adults to control decisions about withholding, refusing, or withdrawing life support.
- (14) The Hemlock Society, which advocates assisted suicide and voluntary euthanasia in cases of terminal illness, is founded in 1980 by Derek Humphrey, who two years earlier had published an account of assisting in the suicide of his terminally ill wife.
- (15) *The Journal of the American Medical Association* publishes "It's Over, Debbie", an anonymous account of active euthanasia written by a house officer, in 1988.<sup>5</sup>
- (16) In the case of Nancy Cruzan, who had been comatose since 1983, the US Supreme Court rules in 1990 that a person whose wishes are clearly known has the right to refuse life-sustaining medical treatment.<sup>6</sup>
- (17) In 1990, Jack Kevorkian, MD, is charged with murder in the death of Janet Adkins, the first in a long and highly publicized series of assisted suicides linked to the Michigan pathologist.<sup>7</sup>

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- (18) In 1991, Derek Humphrey publishes *Final Exit*, which contains suicide "how-to" advice for terminally ill persons and achieves widespread readership.<sup>8</sup>
- (19) In 1991, a National Opinion Research Center poll reveals that legalized euthanasia by physicians at the request of terminally ill patients is supported by over 60% of Americans.<sup>9</sup>
- (20) Timothy Quill, MD, a New York internist, describes in *The New England Journal of Medicine* in 1991 how he assisted a leukemia patient's suicide by prescribing a lethal quantity of barbiturates. His soul-searching account is viewed by many as the antithesis of Dr. Kevorkian's techniques.<sup>10</sup>
- (21) The emergence of Acquired Immunodeficiency Syndrome (AIDS) has had significant impact in turning society's attention toward end-of-life decision making. This tragic illness that affects predominantly young adults and is very frequently fatal has dramatically increased an entire generation's awareness of its own mortality. Among persons who have contracted AIDS, the questions shift away from "Will I die?" to "Where would I like to be when I die?" and "How would I like to die?" and "Who will be with me when I die?" The struggles of these individuals to face the philosophical and practical aspects of their mortality have brought a myriad of end-of-life issues out of the shadows and into the light.

### **Legal Issues at the End of Life**

- (22) The following definitions may help to clarify discussions about end-of-life decisions.
- (23) **Suicide:** the intentional taking of one's own life.
- (24) **Assisted suicide:** providing information, medication (or other means) or direct assistance that enables a person to take his or her own life. The final action remains with the person who wishes to die.
- (25) **Euthanasia:** deliberately bringing about the death of another to spare the individual suffering. In this context, a painless and humane death delivered to a person who is terminally ill.
- (26) **Passive euthanasia:** the act of withdrawing support or intervention necessary to keep a patient alive, such as unplugging a ventilator or stopping parenteral feeding.
- (27) **Active euthanasia:** direct intervention by another person to cause death, for example, by injecting a lethal dose of a drug.
- (28) **Voluntary euthanasia:** performed on a patient who has made clear the wish to die, but is unable to act on it.<sup>11</sup>

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- (29) **Double effect euthanasia:** provision of palliative treatment that may have fatal side effects; i.e., steadily rising doses of morphine, intended to control pain and agitation, also "inadvertently" hasten death by depressing respiration.<sup>12</sup>
- (30) **Terminal sedation:** after removal of life sustaining devices, a person is heavily sedated for comfort until death occurs.
- (31) **Advance directive:** explicit instructions and guidelines regarding an individual's desires for treatment, comfort, and resuscitative efforts in the event of terminal illness or incapacitation.
- (32) Suicide or attempted suicide, while not technically legal, is not prosecuted or punished in any state. All states, however, have prohibitions on intentionally causing the death of another or inducing an individual to commit suicide. At present, assisted suicide is explicitly banned in at least 30 states.<sup>13</sup> On March 6, 1996, the first physician-assisted suicide case decided at the federal appellate level found a Washington state ban on physician-assisted suicide to be unconstitutional. The law in question had allowed "passive" withdrawal or withholding of life support, but prohibited "active" assisted suicide. The decision by the US Court of Appeals for the Ninth Circuit affirmed and clarified a 1994 judgment that had declared the state law unconstitutional. In an 8-3 decision, the appellate court stated, "We hold that insofar as the Washington statute prohibits physicians from prescribing life-ending medication for use by terminally ill, competent adults who wish to hasten their own deaths, it violates the Due Process Clause of the Fourteenth Amendment (to the US Constitution)."<sup>14</sup>
- (33) Less than a month after the Ninth Circuit Court decision, the US Court of Appeals for the Second Circuit struck down a New York law prohibiting assisted suicide. The court found the state had no rational basis for distinguishing between competent, terminally ill patients who may legally choose to refuse medical treatment or have care withdrawn, and patients who choose to end their lives by self-administration of drugs prescribed by their physicians. The court held that "physicians who are willing to do so may prescribe drugs to be self-administered by mentally competent patients who seek to end their lives during the final stages of a terminal illness."<sup>15</sup>
- (34) The states of Washington and New York appealed the two circuit court decisions to the US Supreme Court, which heard the case on January 8, 1997. Observers believe the court is unlikely to rule that terminally ill patients have a constitutionally protected right to assisted suicide. A ruling against a constitutional right will throw the issue back into state legislatures and courts.<sup>16</sup>
- (35) Reviews of the legal literature have failed to identify any cases in which a physician was convicted for helping a suffering patient to die at the patient's request.<sup>17</sup> The risk of criminal liability in withdrawing or withholding life support at the request of a patient or surrogate is exceedingly small. Risk increases somewhat if a clinician directly causes a patient's death by administering a lethal dose of medicine. "Assisting" in a suicide by providing medical advice or means (e.g., a prescription) also carries significant risk of

prosecution.<sup>18</sup> Conviction in such cases is rare if the clinician has acted ethically and compassionately in accordance with the patient's wishes.

- (36) Recently, several states have mounted efforts to legalize assisted suicide. A 1991 initiative -- also in the state of Washington -- was defeated in a general election by a 54 to 46% vote. Although the bill's underlying premise seemed to elicit substantial support, there was also strong concern about inadequate safeguards against potential abuse. A year later, a similar initiative in California with broader safeguards was defeated by a similar margin. In 1994, Oregon voters passed a measure permitting a physician to supply a terminally ill patient with a prescription for a lethal amount of drugs. The hotly contested bill, which passed by a narrow margin, was actively opposed by the American Medical Association, and its implementation has been blocked by litigation.<sup>19</sup>
- (37) The debate over assisted suicide points up the distinction between *legalizing* an action and *decriminalizing* it. Legalization makes an action legal in a defined set of circumstances. Decriminalization maintains the prohibition against an action, but reduces the gravity of the charge and the severity of the penalty, usually to a misdemeanor. Absence of criminal liability by no means precludes the possibility of civil liability, such as suits for medical malpractice or wrongful death.
- (38) Another law that has exerted substantial impact on end-of-life decision making is the Patient Self-Determination Act (PL 101-508, 104 Stat 1388-321), enacted as an amendment to Medicare statutes in 1990. This act required states to develop or enact measures to inform patients of their decision making rights regarding treatment, life support, and resuscitation. Details vary from state to state, but the goal of alerting patients to their options regarding advance directives upon admission to a hospital or nursing home has been broadly realized.

### **Ethical Considerations**

- (39) Ethics, or principles of moral conduct, are not fixed and static, but subject to change and interpretation. Social, historical, cultural, racial, political, professional, and religious influences all shape the ethical beliefs that affect the actions of health care providers and patients.
- (40) Four generally accepted principles of bioethics are autonomy, beneficence, nonmaleficence, and justice.
- (41) **Autonomy**, strictly speaking, is self-rule. To be truly autonomous, one must be capable of making decisions and choices.<sup>20</sup>
- (42) **Beneficence** is acting in what is (or is judged to be) the patient's best interest. It is often equated with paternalism.
- (43) **Nonmaleficence** means to do no harm, to impose no unnecessary or unacceptable burden upon the patient.

- (44) **Justice** means that patients in similar circumstances should receive similar care. It also refers to norms for the fair distribution of resources, risks, and costs.
- (45) For centuries, the healing professions, like the clergy, assumed a parental role. Physicians possessed a storehouse of scientific knowledge not accessible to the general public. Their healing endeavors were often cloaked in ritual and quasi-mysticism. Patients were considered incapable of choosing among complicated scientific theories, and physicians were expected to choose for them. Thus emerged the concept of the beneficent healer, and society came to accept medical paternalism and beneficence as one.
- (46) Over the past three decades, a gradual but inexorable shift has taken place in the field of bioethics. Patients have become better educated and more capable of understanding scientific data. Medicine has become more accessible and somewhat de-mystified. From the mid-1960s on, authority figures -- physicians included -- have been subject to more challenge and scrutiny. As money has become more a focus of health care decisions and debate, physicians' aura of moral authority has eroded.
- (47) In this milieu of change, patient autonomy has evolved as the primary precept of bioethics. In the last 20 years, substantial reforms have been undertaken in the fields of law, ethics, and medical education, all revolving around the patient's right to choose.<sup>1</sup> Often, it is assumed that the principles of autonomy and beneficence are in conflict. This is true if one equates beneficence and paternalism, but the terms are not equivalent or interchangeable. In some circumstances, paternalism might be maleficent -- for example, if it violates a patient's right to choose. And beneficence may be far from paternal, since it may consist of educating the patient to enable his or her informed choice. Beneficence may complement autonomy.
- (48) Nonmaleficence as an ethical principle requires that a provider "first, do no harm." This is a tangled issue in end-of-life decision making, since the same acts may be interpreted as harmful or beneficial depending on the circumstances and on participants' values and perspectives. For example, if a comatose patient with no advance directive is kept on life support in the ICU, is not harm inflicted through physical discomfort and financial hardship? On the other hand, if life support is withdrawn, is the patient not harmed by being deprived of even the remotest chance of recovery?
- (49) The principle of justice is not a simplistic implication that all patients should receive the same treatments and resources. It does require that all patients be accorded respect for their individuality and autonomy. All should receive the same opportunity to be informed and choose their course of treatment. It also requires that scarce resources be allocated fairly (for example, on patients with a good chance of recovery rather than on those for whom treatment will be futile).<sup>21</sup>

### **Cooperative End-of-Life Decision Making**

- (50) A society's beliefs are reflected in its laws and ethical principles. The individual struggling with difficult decisions about death and dying can turn to those principles for guidance, but will rarely find that they provide all the answers. Ultimately, death is not societal but solitary and supremely personal. However, as medicine has succeeded in prolonging life, greater numbers of people have become enmeshed in the process of an individual's death. At the dying patient's bedside are family, loved ones, clergy, health care providers, technicians and, in absentia, lawyers, ethicists, and even third-party payers. Each brings a set of priorities, beliefs, and values, and achieving complete harmony among them is usually impossible. If the goal of end-of-life decision making is to make the process of dying as humane and compassionate as possible, it is essential to minimize conflict and maximize cooperation for the patient's benefit. One way to enhance cooperation is by understanding the internal and external influences that affect the patient, his or her family, and clinicians, especially physicians and PAs.

### **Patient and family concerns**

- (51) Often, the first question asked by patient or family in cases of serious illness or injury is, "Is this condition terminal?" If death seems imminent, the next question is almost always, "How much time is left?" The longing for certainty is natural, but these questions are usually impossible to answer satisfactorily. PAs and physicians have seen too many unexpected deaths and unforeseen recoveries to make firm predictions or speak in absolute terms. Patients and families may then become frustrated by what they perceive as a lack of competence, concern, or communication. They want answers, which the clinician often simply cannot provide -- sometimes giving rise to an adversarial relationship.
- (52) The next big question often pertains to suffering. "Will I be in pain? Can you control it? Will I have to be sedated or unconscious in order to be comfortable?" Studies have shown that many patients fear pain less than the loss of control.<sup>22</sup>
- (53) Finances are a third major concern for patients and families. "What will all this care cost? Is it covered by insurance? Will my family or loved ones be bankrupted to provide me with a few extra days or weeks of existence?"
- (54) Faced with the prospects of uncertainty, pain, loss of control, and financial ruin, some patients and families begin to consider options other than intensive medical intervention. They may choose no therapy other than pain control (palliative therapy). They may even consider suicide, assisted suicide, or some form of euthanasia.
- (55) PAs should be prepared and willing to discuss advance directives and living wills with their patients. Concerns with advance directives often center around several areas:

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- (56) Families may believe their loved one is not competent or capable enough to formulate an informed advance directive. They may believe the patient is too upset to be rational or doesn't understand all the options.
- (57) Patients often worry that family members will contradict their advance directive.
- (58) Patients and families are concerned lest physicians override their wishes. In fact, some studies suggest that physicians may do just that in up to 25% of cases, even when the wishes of the patient were clear.<sup>23,24</sup>
- (59) In situations where patients decline to draw up an advance directive or living will, they should at least be encouraged to enact a health-care power of attorney, designating a family member, loved one, or friend as a surrogate with the authority to make medical care decisions for an incapacitated individual. This may avoid the "majority rule" mode of decision making that often arises when no advance directive exists.
- (60) Patients and families should also learn about the availability of home care and hospice services. Hospice in particular can be an invaluable resource. Not only do the volunteers and nurses provide bedside care and family support, but they can also assist with education, planning, and accessing social services.
- (61) Questions of a moral or religious nature often arise in end-of-life decisions. In Western culture, matters of life and death have been traditionally presumed to be in God's hands. As technology has placed more moral weight onto human shoulders, many patients feel guilt over wishing for death or asking to die. They fear condemnation for choosing the time and manner of their own death, and may seek moral validation through the active or tacit approval and even the assistance of others, especially "authority" figures such as a clergy member, physician, or PA.
- (62) The major premises of American bioethics are based on values that are predominately western, white, and middle class. The values and beliefs of other races and cultures may differ significantly. For example, the perception and expression of pain is significantly influenced by cultural and racial factors. At the end of life, cultures that are more family oriented, such as Korean, Chinese, or Mexican, may place much less emphasis on patient autonomy and fully-informed individual consent. Others may be likely to insist on aggressive, life-sustaining treatment. Studies have shown that substantially fewer minority patients make use of advance directives, even when such directives are readily available.<sup>25</sup>
- (63) While it is wrong to ignore the effects of culture and ethnicity on end-of-life planning, it is equally wrong to assume that all members of a particular cultural or ethnic heritage share the same values and beliefs. Providers must individualize their care of dying patients and their families, while remaining sensitive to cultural variables such as language, family dynamics, religion, economics, pain behaviors, and alternative healing practices. In some situations, providers may need to seek assistance from religious leaders, traditional healers, translators, and cultural consultants.<sup>25</sup>

**Evaluating requests for assistance in dying**

- (64) End-of-life decisions are influenced by factors including uncertainty, fear, pain, ethical and moral concerns, financial factors, and family support (or lack of it). When patients express a desire for active involvement in their own death in any manner, family and providers should carefully evaluate their state of mind and intent. Such requests may actually represent:
  - (65) feelings of abandonment by family or the medical establishment.
  - (66) desire for more effective symptom control, or simply more control over treatment and surroundings.
  - (67) concern about becoming a financial burden.
  - (68) clinical depression. (Terminally ill patients often suffer from depression, and it is wrong to assume that it is a natural part of the disease process; treatment often improves quality of life.)
  - (69) reaction to real or perceived conflicts with family members, or a belief that others expect them to "pass away quietly."
  - (70) Determining true intent at this stressful juncture can be very difficult. A person may request death because no other reasonable options seem possible. Thus, some requests may be interpreted as an invitation to better and more open communication, rather than a genuine wish to die.<sup>26</sup>
  - (71) As a final guideline in conflicts over end-of-life decision making, clinicians and family members should recall the first principle of bioethics: patient autonomy. The patient's right to choose is primary, provided that the choice is informed, uncoerced, and does not seriously conflict with the autonomy of others.

**Caregivers' concerns**

- (72) For physicians, PAs, and other caregivers, the death of a patient is a complicated and trying event, provoking a host of ambivalent thoughts and feelings. Clinicians must meet the emotional, ethical, and legal challenges of caring for the dying while maintaining their own personal and professional integrity and values.
- (73) The relationship of patient to health care provider is a two-way interaction with mutual obligations, uncertainties, and rewards. Events affect both parties; beliefs and values of one may subtly or overtly affect the other. Those who care for the dying owe it to their patients and themselves to scrutinize their own attitudes, which may influence the kind of care they deliver.

- (74) Many studies have shown that the values, beliefs, and emotional health of the clinician are an integral part of the care and counseling given to the dying person.<sup>27</sup> For example, patient choices depend not only on what information is given, but also how it is presented. Up to 20% of patients who have chosen a particular option will change their mind if the information is presented differently.<sup>28</sup> A 1990 study showed that physician recommendations to withdraw life support in the ICU were rejected by patient or family only 2% of the time.<sup>29</sup>
- (75) Diagnosis appears to affect physician attitudes about discussing resuscitation or do-not-resuscitate (DNR) orders. One study documented that up to 50% of AIDS and cancer patients had been involved in such decisions, but only 5 to 15% of patients with cirrhosis or congestive heart failure had such involvement, despite similar severity of illness and prognosis.<sup>30</sup> Physicians have been documented as underestimating chronically ill patients' quality of life, and may incorrectly assume that such persons would wish to refuse life-sustaining interventions.<sup>31</sup> And, unfortunately, undertreatment of the pain, agitation, and depression associated with terminal illnesses persists.<sup>32,33</sup> Treatment decisions may be strongly influenced by the provider's own anxieties about the prospects of disability, aging, and death.<sup>27</sup> Recent studies have shown that clinicians are reluctant to discuss advance directives with many patients who would welcome such a discussion. Their own opinions as to the appropriateness of resuscitating a patient were identified as strong determinants of whether or not such discussions were initiated.<sup>24,34</sup>
- (76) The evidence is compelling: those who care for dying patients must examine and understand their own feelings, beliefs, and limitations regarding the process of dying. Caregivers often try, consciously or not, to validate their own beliefs by convincing others to share them. Religious and moral convictions are subject to infinite shadings and interpretations. Clinicians who are aware of, and comfortable with, their own beliefs are less likely to feel either conflicted or compromised.
- (77) Physician assistants must recognize their own values with regard to pain and suffering and the physical process of dying. Many clinicians seem to value stoicism in themselves and others; they rarely ask for help and may look down on those who do. Others are so uncomfortable with human suffering that, if they cannot relieve it, they withdraw.<sup>27</sup> Some value alertness and control over comfort in their own lives. By projecting their values and priorities onto the care of a dying patient, clinicians may make incorrect assumptions about the patient's wishes for sedation and symptom control.
- (78) Supporting patient autonomy may be easier said than done. Here is a short "examination of conscience" for clinicians:
- (79) Do I feel challenged or threatened if a patient questions my judgment or seeks another opinion?
- (80) Do I often disagree with patients over treatment plans?
- (81) Do I ever initiate tests or treatments without discussing them first, on the assumption that I know best?

- (82) Do I ever ignore a patient's specific directives, thinking that they just don't apply in this circumstance?

**The clinician's comfort zone**

- (83) The autonomy of the health care provider matters, too. Clinicians possess expert knowledge and should be free to use it in their best judgment. Respect for patient autonomy does not obligate the use of unproven or inappropriate treatment modalities. The clinician's morals and ethics must also be respected. If they conflict with those of the patient, the patient should be notified and allowed to seek another caregiver with more compatible attitudes and values.
- (84) Care for the terminally ill covers a range bounded by two extremes, from "do everything possible to sustain life" to "active euthanasia." In between lie all the subtle gradations of care: palliation, non-initiation of life support, withdrawal of mechanical support, withdrawal of nutritional support, terminal sedation, suicide, assisted suicide. No one can identify a single position on the continuum and apply it to every case. However, it is equally impossible for most clinicians to be comfortable from one end of the range to the other.
- (85) Rather, clinicians must establish a "comfort zone" wherein they can provide maximum benefit to the patient while adhering to their own moral convictions. The breadth and position of this comfort zone may change over time as skills and experience are gained.

**Private Decisions, Public Demands**

- (86) While end-of-life decisions are made in a very private setting, the framework upon which these decisions are based is shaped in the public arena. Some difficult questions cannot be addressed on the individual level, and society must make these broader decisions.
- (87) Strong arguments for and against liberalization of assisted suicide and euthanasia have raged over the past two decades. Legalization efforts have met with mixed results: two initiatives have been defeated in general elections and a third passed with the narrowest of margins. Legislative measures were introduced in at least 12 states during the 1994-95 sessions. At last report, all had failed.
- (88) But public attitudes are complex. Even as voters and legislators seem to be sending a message of restraint, jurors continue to acquit Kevorkian of murder for assisting in suicides in ways that would have violated the provisions of the ill-fated Washington and California initiatives as well as the more restrictive Oregon measure.<sup>7, 19</sup> A recent poll of Michigan adults reported that 71% opposed trying Dr. Kevorkian on murder charges. Other polls consistently find that at least 60% of the American public support liberalizing restrictions on assisted suicide.<sup>9, 35</sup> The public seems to be speaking with two loud but contradictory voices. Americans have yet to approve assisted suicide or euthanasia at any level, yet they also appear reluctant to formally condemn it.

- (89) Opponents of liberalization often cite the so-called "slippery slope" argument: once restrictions are loosened, the process will be difficult to regulate and control.<sup>11, 36</sup> Those who fear the liberalized "slippery slope" express concerns that economically and socially vulnerable patients (for example, the poor, homeless, imprisoned, or disabled) may be inappropriately encouraged or "assisted" with suicide. They often point to the Dutch experience, which has found that in some cases of euthanasia, no request for assisted dying was documented.<sup>2</sup> As Steven Miles, MD, has stated, "Law is too blunt an instrument and the psychology of 'rational' or 'irrational' suicides...is too murky to selectively empower only 'good' decisions by 'ideal' physicians. The legalization of assisted suicide would empower not only physicians with good relationships (with their patients), but also those with transient, inadequate, or troubled relationships."<sup>27</sup>
- (90) However, there may be more than one slippery slope. Just as liberalization of assisted suicide could have unintended consequences, so too could absolute restriction on assisted suicide. For example, in many cases a patient's request for assistance with suicide leads to a dialogue that results not in death, but in improved communication, better symptom control, and more appropriate use of available resources. Providers who fear criminal prosecution may be reluctant to enter into any discussion in which the patient mentions suicide or assistance with suicide. This could have a profoundly chilling effect on provider-patient communication.
- (91) Judging from the public record, society wants change -- but they want it to be cautious and considered. Americans seem to want a legal framework that allows for compassion and flexibility but protects against abuse. One answer may be decriminalization within well-defined guidelines. For example, the recently passed Oregon initiative required that a patient's request be in writing and signed before two witnesses who agree that the patient is competent and acting voluntarily. Two physicians must agree that the patient is terminally ill and likely to die within six months, and counseling is required if depression is suspected.<sup>19</sup> Timothy Quill, MD, has suggested additional guidelines that are admirable in intent but may be difficult to comply with. For example, "the physician must be sure that the patient's judgment is not distorted." Certainty in this regard may be elusive. Other guidelines suggested by Quill are more concrete, such as the need for clear documentation and mandatory consultation.<sup>22</sup> Various criteria also exist for DNR orders and withdrawal of life support.<sup>37</sup> While clinicians, legislators and ethicists may propose guidelines, it will remain society's responsibility to adopt and abide by them.

### **Cost and justice**

- (92) Inevitably, issues of cost will play a part in this debate. The financial burdens of a lingering death loom large in end-of-life decision making, but the costs of facilitating death are seldom considered. Legal advice, financial consultation, psychological testing and treatment, mandatory medical consultations, increased record keeping, and the activity of ethics committees all require money.
- (93) Issues of access and justice also arise. In theory, all patients who need such services should be able to access them. In reality, will society extend end-of-life options to the

uneducated, uninsured and impoverished? Will those in special populations, including managed care organizations and programs such as Medicare and Medicaid, have equal opportunity for any benefits that arise from policy reform?

### **Special Concerns for Physician Assistants**

- (94) The patient is the central figure in end-of-life decision making, but physician assistants have an important role to play. In some cases, the PA will be the dying patient's primary health care provider and chief advocate. All medical caregivers have a prime responsibility to ensure the patient's well-being. In doing so, however, they must act in accordance with their own ethical principles. PAs also have a unique responsibility arising from their relationship with supervising physicians, who share liability for the PAs' actions.
- (95) Within this context, it is easy to imagine scenarios that could place PAs in awkward or troublesome situations:
- (96) Against a dying patient's wishes, a supervising physician intervenes in the patient's well-established relationship with a PA.
- (97) A patient requests a PA's assistance in making or implementing end-of-life decisions, but a physician ethically opposed to the chosen course forbids the PA's participation.
- (98) A physician is willing to grant a patient's request for withdrawal of life support, although the PA strongly recommends consideration of other issues such as depression or pain control.
- (99) A PA has two supervising physicians who share call and hospital duties, but have widely divergent moral and/or ethical views on end-of-life issues.
- (100) A precarious spot and divided loyalties may characterize the PA's position in such circumstances. The optimal course is to discuss end-of-life issues with the supervising physician before potential conflicts arise. When discord persists, the PA must remember that the physician bears the ultimate liability and, therefore, the final responsibility for clinical decision making. A PA who believes that legal or ethical precepts are being violated is responsible for speaking out in an appropriate and timely manner.<sup>38</sup>

### **Conclusion**

- (101) Life is a process with death as an integral part of the continuum. In the past, death has sometimes been relegated to a separate and distinct entity, isolated from human experience -- an interruption, an end, a form of oblivion. Science has given us the ability to prolong, sometimes indefinitely, the process of dying. With this ability comes the awesome responsibility of deciding when and how to use it. American society has been struggling with this responsibility. In recent years the contentious, sometimes heated, debate has spread from the bedside to legislative chambers and courtrooms.

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- (102) Even though many questions remain to be answered, the debate has helped focus attention on one undeniable fact. Our society and our profession have much room for improvement in the care of those who are near the end of their lives. The real issues and problems are much more complex and far-reaching than the relatively narrow question of assisted suicide. Although this is a crucial and controversial question, perhaps its truest benefit has been to open and broaden the discussion of other issues surrounding end-of-life decision making.
- (103) Not one of these issues exists in a vacuum, nor will most be resolved soon. That does not mean that improvements cannot take place as the debate continues. In light of the discussion presented in this paper, the American Academy of Physician Assistants believes that:
  - (104) The ethical principles of patient autonomy and informed choice are of primary importance in end-of-life decision making. The autonomy of the health care provider must also be respected. Laws, policies, or unwritten rules that interfere with communication between provider and patient, or that inappropriately restrict patient autonomy, should be condemned.
  - (105) Physician assistants and other providers who care for dying patients must be knowledgeable in managing that care. They should be able to recognize and treat physical and psychological conditions that adversely affect the patient's comfort and emotional well-being. These providers should have specific and appropriate training in pain management and in the counseling of dying patients and their families.
  - (106) End-of-life decision making is far more inclusive than limited discussions of assisted suicide or euthanasia. "Assistance in dying" includes many interrelated aspects -- from planning, counseling, and advance directives to clinical care. Every point on the continuum of clinical care has unique moral, ethical, and legal implications for both patient and provider. A well-established therapeutic relationship with a clinician, based on mutual trust, respect, knowledge, and understanding, is essential to assisting a patient with any of these critical issues and decisions.
  - (107) Information about advance directives should be available in all health care settings, including outpatient clinics, home health agencies, pharmacies, and public health facilities. Physician assistants should be prepared and willing to discuss advance directives with their patients.
  - (108) Physician assistants have a legal and ethical responsibility to the supervising physician, as well as to the patient. PAs should inform and involve the physician in all near-death planning. The PA should not withdraw life support without the supervising physician's agreement.
  - (109) In some circumstances, certain terminally ill patients may find a dignified and painless death by suicide preferable to a continued life of pain and suffering. However, physician

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assistants and all providers must recognize that not all patients who request assistance with suicide really wish to die. They may suffer from depression, need better symptom control, or need more information to better understand their options.

- (110) Any request for assistance and support from a terminally ill patient, whether or not it involves suicide, should be treated seriously and respectfully. PAs should be aware that their comments, demeanor, and attitudes can profoundly affect patients who are in a suggestible and vulnerable time of their lives.
- (111) The AAPA does not advocate assisted suicide. However, the AAPA feels that the ethical, compassionate, well-intentioned provider who discusses voluntary self-termination of life by competent informed terminally ill patients is not to be subject to prosecution.
- (112) Physician assistants are front line caregivers for the dying. They should take a leadership role in educating the public, policymakers, other health professionals, and their patients regarding the need for enlightened and progressive policies in this area. The AAPA believes that the most effective way to minimize the issue of assisted suicide is to optimize care and maximize quality of life for patients at the end of life.

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