

IMPROVING CARE AT LIFE'S END

REPORT OF THE CALIFORNIA MEDIATED
PUBLIC POLICY DIALOGUE ON PHYSICIAN-ASSISTED
SUICIDE AND END-OF-LIFE ISSUES

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INTRODUCTION

Richard died at 62. He had been diagnosed with colon cancer. He presumed that his lower back pain was temporary, the result of too much golf or lifting something too heavy. By the time the true cause was known, the cancer had spread to his liver. At each turn in his treatment, he imagined that the next round of chemotherapy would end the disease. When the oncologist told him that more treatment would not be beneficial, he began, in earnest, to contemplate the end of his life. He had learned to live with pain and he wondered whether the pain to come might be difficult, even impossible, to bear. He asked himself whether medication sufficient to relieve the pain would leave him unable to communicate with his wife of 41 years or cause him to become dependent, even addicted. He feared that his care would burden his family, depleting limited resources and imposing on loved ones. He agonized over his impending dependence. He dreaded the idea that he would more than likely die in an unfamiliar place. He wondered whether the doctor who seemed so certain of how to treat his illness knew how to respond now that no cure seemed possible.

The story above is based on the dying experience of a real person. Each year, more than 200,000 Californians die. The quality of the care they receive, the support they are offered, and the understanding that they and loved ones have of end-of-life issues varies widely.

In survey after survey, when asked how they would hope to spend the last days of their life, an over-

whelming majority of people say that they want to die at home, free of pain, and surrounded by loved ones. Often, the reality is exactly the opposite; we tend to die alone, in institutions, in pain, receiving inadequate treatment or treatment inappropriate to our prognosis or without clear documentation of and respect for our hopes and needs.

The hospice movement has done a great deal to improve the dying process. Fundamental to the hospice movement is the belief that a person's final days can be filled with a richness of human experience that can be obscured by healthcare's traditional focus on curing. Despite the clear benefits of hospice and other forms of high-quality end-of-life care, too many still die in settings that do not support anyone's idea of a good death.

The current reality can be characterized in this way:

- Too few have access to excellent end-of-life care, including hospice, palliative care, and emotional, spiritual and psychological support.
- There is insufficient attention to and funding for home-based care that could keep people who are dying from spending their last days in a hospital.
- Medical and nursing schools place too little importance on pain management, end-of-life care, suffering, family needs and the wishes of patients.
- Doctors and nurses have too few mentors who can guide their understanding about end-of-life issues.
- The general public has too few opportunities and is reluctant to learn about death, the dying process and emotional, spiritual, mental and physical needs at life's end.
- Fear of addiction and misguided drug abuse prevention strategies (such as the triplicate prescription requirement) prevent appropriate responses to pain.
- Financial reimbursement for palliative care is sorely insufficient.
- Those who are dying and their loved ones, who have to navigate the healthcare system, must contend with conflicting laws, regulations, and agency mandates.

NOTE ON LANGUAGE: PHYSICIAN-ASSISTED SUICIDE/ PHYSICIAN AID IN DYING

The participants in this dialogue could not reach consensus on a neutral term and agreed to use both physician-assisted suicide and physician aid in dying for the purposes of this dialogue only. Proponents of changing law call the act "physician aid in dying." They believe that the phrase "physician-assisted suicide" is a pejorative term that skews the public debate about this serious public policy issue. For those who wish to maintain the current protections, the term physician-assisted suicide still accurately describes the practice, does not confuse this act with legal physician assistance in dying and conveys the import of what changing the law might involve. Depending on context, both are used in this report.

A DIALOGUE ON END-OF-LIFE ISSUES

At the request of the Select Committee on Palliative Care of the California State Assembly, a group of

stakeholders and interested individuals representing a wide array of organizations, constituencies and points of view met to discuss end-of-life issues. A list of those who participated is included on page 14. The Select Committee asked participants to discuss two issues:

- How to improve the dying process, with a focus on public policy recommendations on end-of-life care; and
- Physician-assisted suicide and the values and policy perspectives that underlie attitudes toward physician-assisted suicide/physician aid in dying.

IMPROVING THE DYING PROCESS

In order to improve the dying process for Californians, participants reached consensus on numerous recommendations. The recommendations are addressed to policymakers, educators, healthcare professionals, foundations and society at large. They include:

- Existing state law needs to be enforced;
- The triplicate prescription requirement should be eliminated;
- Unfounded fear of drug addiction needs to be addressed;
- Healthcare education and requirements for licensure must address end-of-life and palliative care issues more effectively;
- Healthcare institutions should comply with the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) pain standards;
- The general public would benefit from better education about death and dying issues;
- Use of advance directives (and the conversations with loved ones and health care providers leading up to completing an advanced directive) should be increased; and
- Barriers to end-of-life care, including financial obstacles, should be removed.

The full text of these recommendations begins on page 2.

PHYSICIAN-ASSISTED SUICIDE/ PHYSICIAN AID IN DYING

Participants discussed the multiple facets of physician-assisted suicide/aid in dying. Participants demonstrated that it is possible to listen to each other's perspectives, and to respect the sincerity of each other's commitments, but they reached no consensus on the proper moral or legal status of this very difficult public policy issue. The group offers no recommendation to the Select Committee on Palliative Care on this matter; however, the concluding section of this document makes the major points (pro and con) on this controversial subject as seen by the advocates of each point of view.

RECOMMENDATIONS TO IMPROVE END-OF-LIFE CARE

The following recommendations arise from a shared sense of urgency about improving the dying process for Californians.

EXISTING STATUTES

Context

We recognize, and want the California State Assembly's Select Committee on Palliative Care to note, that laws already exist which, if fully implemented, would have a beneficial impact on end-of-life care. Lack of monitoring, unimplemented and unfunded mandates and conflicting legislative direction on subjects such as the Pain Patients' Bill of Rights of 1997 and Right of Control laws deserve legislative attention.ⁱ

Recommendation

The Select Committee should hold hearings to determine whether existing laws that would have a beneficial impact on end-of-life care are being implemented to their fullest extent and are compatible with other current statutes and regulations.

TRIPPLICATE PRESCRIPTIONS

Context

Numerous nationwide surveys have clearly documented that triplicate prescriptions pose a significant barrier to good pain management.ⁱⁱ For example, more than one-half of physicians surveyed by Weissman et.al. reported that they would reduce the dose or quantity or choose a drug in a lower schedule because of concern about regulatory scrutiny. Similar patterns hold for California. J.F. Skelly reported a study in which 69 percent of California physicians surveyed stated that the risk of disciplinary action made them more reluctant to use opioids in pain management. One-third reported that their patients might be suffering from neglected, treatable pain. In 1994, the California State Legislature sponsored a Pain Summit at which participants concluded that the most profound and egregious barrier to adequate pain management in California is the triplicate prescription requirement. The report from the Pain Summit states, "The triplicate prescription system—which must be used when Schedule II controlled substances are prescribed—is outdated, impractical for many modern health care settings (especially long-term care) and generally ineffective for monitoring and controlling diversion of medications for non-therapeutic purposes. The triplicate system should be replaced with an electronic prescription monitoring system as soon as possible."

In 1996 the State Legislature established such a system: the Controlled Substance Utilization Review and Evaluation System (CURES). Under the authority of the Department of Justice (DOJ), CURES was established for the electronic monitoring of the prescribing and dispensing of Schedule II controlled substances by all practitioners authorized to prescribe or dispense these controlled substances. CURES was implemented as a three-year pilot project (commencing on July 1, 1997). According to the 1999 CURES Report, CURES had been implemented in a timely and cost-effective manner. The report made several recommendations, including making CURES permanent.

Recommendations

1. The California State Legislature should eliminate the triplicate prescription requirement in California, replacing it with a technologically appropriate system.
2. The State Legislature should take all necessary steps to ensure that the Controlled Substance Utilization Review and Evaluation System (CURES) addresses law enforcement concerns (i.e. lack of hard copy and security).
3. The State Legislature should make CURES permanent.
4. The State Legislature should institute a system to share drug utilization data from the CURES system with individual patients' physicians and pharmacists in order to assist those who are addicted or apprehend those engaging in drug diversion activities.

UNFOUNDED FEAR OF ADDICTIONⁱⁱⁱ

Context

One consistently identified barrier to effective pain relief is an unfounded fear on the part of healthcare professionals, patients, and families that opioid analgesics carry a high risk of addiction. This fear is in turn based upon a failure to properly distinguish between physiological dependence on opioids, which is a natural consequence of the long-term administration of opioids and not a contraindication to their use, and the abuse of opioids that is characteristic of addiction. The best medical evidence demonstrates that the risk of addiction from appropriate long-term administration of opioids for moderate to severe chronic pain is less than .01 percent.^{iv}

The Drug Enforcement Administration's (DEA) *Physicians' Manual* states: "Controlled substances, and in particular, [opioids], may be used in the treatment of pain experienced by a patient with a terminal illness or chronic disorder. These drugs have a legitimate clinical use and the physician should not hesitate to prescribe or administer them when they are indicated for a legitimate medical purpose."

Similarly, the Medical Board of California policy states that "Federal and California law clearly recognize that it is a legitimate medical practice for physicians to prescribe controlled substances for the treatment of pain, including intractable pain ... Concerns about regulatory scrutiny should not make physicians who follow appropriate guidelines reluctant to prescribe or administer controlled substances, including Schedule II drugs, for patients with a legitimate medical need for them."

Recommendations

1. Healthcare professional programs should interpret the continuing medical education (CME) requirements of AB 487^{vii} as requiring, as an essential element of a pain management or end-of-life curriculum, instruction in current information on the difference between addiction and physiological dependence, the risks and side effects of opioid analgesics and how to minimize or safely and effectively manage them, as well as strategies for educating patients and families about the risks and benefits of various pain management strategies.
2. Healthcare institutions and organizations in the state should provide public education programs on topics related to end-of-life care, with an emphasis on addressing common fears and misconceptions about palliative interventions and end-of-life care.

HEALTHCARE EDUCATION

Context

Efforts to improve end-of-life care must begin with the training of healthcare professionals. Medical and nursing school curricula do not focus sufficiently on palliative care, hospice care, and pain management. In addition, students do not find adequate mentoring in end-of-life care and exposure to the professional values of protecting the vulnerable and relieving pain. Both AB 487^{vii} and AB 791^{viii} need to be meaningfully implemented as part of the training improvement.

Centers of Excellence fund programs targeted toward a particular disease or health problem to provide a critical mass of expertise to accelerate advances in research, teaching, and care. Typically, Centers are composed of multi-disciplinary teams that include prominent

researchers, clinicians, and educators. They often use a multi-disciplinary model with nurses, physicians, social workers, psychologists, and other staff. Center staff members provide clinical care, teach residents and fellows, and conduct applied, clinical research. Centers can also work to translate research advances into community practice through public and professional education. Since pain management and palliative care involve multiple disciplines (e.g., medicine, nursing, pharmacy, social work, etc.), and since the current capacity with respect to research, teaching, and care is limited in the state's nursing and medical schools, the Centers of Excellence approach may accelerate improvements in these areas, as it has in other health areas.

Sub-specialties are specific areas of training and expertise in medicine. Expansion of the number of healthcare professionals with sub-specialty training and/or certification in palliative care will enhance the quality of end-of-life care and provide additional resources for the education of healthcare professionals in the core competencies of end-of-life care. A sub-specialty of palliative care exists in other countries, such as Canada.

Recommendations

1. Healthcare professionals' training programs should devote adequate attention in their curricula to pain management, palliative care, appropriate end-of-life care and the ethical issues associated with aggressive pain management.* Programs should provide didactic instruction during the basic science years and exposure separate from general clerkships during the clinical years. Clinical teaching should include, but not be limited to, rotations on services specializing in pain management, palliative medicine, and hospice care.
2. The State Legislature, California foundations or both should fund the development of a statewide program supporting research and pilot intervention projects aimed at enhancing medical and nursing education in pain management and palliative care. This includes undergraduate, residency, and fellowship medical education and training, as well as undergraduate and graduate nursing education and training.
3. The State Legislature, private foundations or both should fund Centers of Excellence at California medical and nursing schools to improve clinical care, teaching, and research in the areas of pain management and palliative care. These Centers could build on the clinical and ethical expertise that is currently available in the state's medical and nursing schools.

*Aggressive pain management with a risk of unintentionally hastening death is not physician-assisted suicide.

4. The State of California and organizations located in the state should fund faculty positions, fellowships, and other training programs conducive to the development of recognized sub-specialists in palliative care. The recognition of and support for a sub-specialty in palliative care should in turn be utilized as a basis to insure that all healthcare professionals in California who provide care to patients with terminal or life-threatening illnesses possess core competencies in end-of-life care. The goal is that board certification will be granted by organizations of medical specialties.
5. The State Legislature or California foundations should fund fellowships and faculty positions in the state's medical and nursing schools aimed at enhancing these institutions' core expertise in palliative and end-of-life care.

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has established accreditation standards for the assessment and management of pain and the education of healthcare professionals, patients, and their families on the importance of prompt and effective pain relief to good patient care. The State of California, through AB 791, has also required that pain be charted as the "Fifth Vital Sign" in all facilities licensed by the state. Implicit in the duty to assess and document a patient's pain is the correlative responsibility to promptly and effectively manage pain consistent with the needs and best interests of the patient.

Experts in end-of-life care consider the current "community standard of practice" for physicians (what reasonable, similarly trained doctors would do under similar circumstances) regarding pain management unacceptably poor. Best practices based on current medical literature, including evidence-based guidelines, should be used as the acceptable standard to which all doctors treating patients at the end of life should be held.

In legal settings, the community standard of care is determined by expert testimony rather than by the Medical Board. Therefore, improvements in the quality of care in pain management and palliative care will occur through advancements in research and teaching that are translated into care in both academic and community settings. The Medical Board imposes sanctions against a physician's license (i.e. discipline) for departures from the community standard of care.

LICENSURE

Context

AB 487 requires 12 hours of continuing medical education (CME) in pain management and end-of-life care (by December 31, 2006) as a condition of licensure for physicians, except radiologists and pathologists. This is an excellent beginning and should be extended to other healthcare professionals, particularly to nurses who so often interact directly with patients in regard to pain management.

Recommendations

1. The State Legislature should institute licensure requirements for nurses similar to those for physicians.
2. Qualified professional associations (the California Medical Association, the American Academy of Pain Medicine and the American Academy of Hospice and Palliative Medicine, etc.) should develop, on an ongoing basis, courses with current, practical content that help to improve the quality of care in pain management and palliative care. Management guidelines and investigative standards that are developed pursuant to AB 487 (Chapter 518) should be incorporated into course content. These courses should be readily available to all physicians and nurses throughout the state. This may require the development of content delivery through distance learning modalities (e.g., downlinked audiovisual programs, Internet modules, etc.).

Recommendations

1. Oversight organizations within the health delivery system (such as the Medical Board of California, peer review committees, and risk managers) should facilitate improved treatment of pain at the end of life so as to create a higher standard of care than the current prevailing community standard.
2. The State of California should support the in-service education of medical and nursing staff that will be essential to ensure compliance with the higher standards, especially in long-term care facilities that are less likely to be accredited by JCAHO.

PAIN STANDARD COMPLIANCE

Context

An institutional commitment to pain management is the first line of defense for patients against undertreated pain.

PUBLIC EDUCATION

Context

Approximately 25.8 million family caregivers provide personal assistance to adults (aged 18+) with a disability or chronic illness and, by the year 2007, the number of caregiving households in the United States for persons aged 50+ could reach 39 million. Families often find they have inadequate preparation and resources to cope with issues of aging, terminal illness, the dying process,

and death. Caregiving and the inevitable loss of a loved one bring emotional, psychological, physical, spiritual, and fiscal consequences that threaten to debilitate and deteriorate the resources of families, caregivers, and governmental programs.

Broadly educating the public about end-of-life care and related issues is as important as, and complementary to, improved medical education. Almost all of California's public, post-secondary education institutions offer undergraduate courses that address end-of-life issues, many of which fulfill requirements for the degree. In many cases, especially in institutions lacking affiliation with a teaching hospital, there is little opportunity for faculty to keep current with, or students to engage with, the realities of the dying process in California.

In implementing each of the educational recommendations, it is important to recognize that California is a very diverse, multicultural state. The 2000 census reveals a picture of California that includes no racial or ethnic majority and literally hundreds of language and cultural groups.

Recommendations

1. State agencies and private organizations concerned with end-of-life care should join with California's universities and colleges to provide workshops and seminars that inform faculty who teach undergraduate students about current treatments and clinicians' perspectives. Publicly funded teaching hospitals should provide professional development opportunities for teachers of undergraduates, as well as continuing education for healthcare professionals. And the California Commission on Improving Life through Service should increase opportunities for undergraduate students to learn through community service with facilities and programs specializing in end-of-life care.
2. The State Legislature or California foundations should fund the development of statewide public educational programs, forums, and seminars in order to address the emotional, physical, and financial fears that contribute to the public's lack of discussion about death and dying. These programs should openly discuss the emotional, physical, and spiritual challenges that aging, dying, and death can impose, while also embracing the contributions that these life events, and the people affected by them, provide to society as a whole. Public education programs should focus on cultural perspectives and the core values shared by all cultures, including the dignity of the human person, the common responsibility for the vulnerable, and the reality of our social obligations to one another.

3. The State Legislature should fund the development of a comprehensive approach to providing information to the public about end-of-life resources. Such an approach might include a listing of "Things to Consider—Planning Ahead" and a "Directory of Statewide Resources/ Services" to assist the patient and family with current and future needs.
4. The Select Committee on Palliative Care should hold hearings to determine how best to expand the availability of training programs and respite resources for family caregivers.

ADVANCE DIRECTIVES AND PLANNING

Context

Significantly increasing the number of persons with formal healthcare directives will enhance the quality of care at the end of life by making it more consistent with patients' values, goals, and priorities. The consistently low percentage of adults with formal directives reflects, in large measure, the extent to which advance care planning has been marginalized in clinical and legal practice and estate planning. Conversations with family members and care providers are an important part of preparing to draft an advanced directive.

Recommendations

Professional healthcare organizations and institutions in California, as part of a minimal standard of acceptable care for primary care physicians, should:

1. Institute measures designed to insure that, as a matter of routine, physicians become acquainted with, document and respect their patients' personal values and wishes.
2. Require that physicians encourage their adult patients and families, regardless of their age or state of health, to execute a healthcare directive, and offer assistance so as to insure that such directives are clear in their discussion of medical interventions;
3. Integrate advance healthcare planning into routine preventive medicine services;
4. Ensure that healthcare directives are entered into the patient's medical record in a highly visible and easily accessible section and that institutional policy ensures that treatment is consistent with these directives; and
5. Establish quality assurance indicators reflecting the correlation between healthcare directive content and clinical practice.

ACCESS TO END-OF-LIFE CARE

Context

The preceding recommendations can, and will, have a significant impact on those who receive care. However, there are barriers that prevent Californians from accessing that care, no matter what its quality. The California State Legislature should take actions to remove those barriers and to ensure that every Californian has the opportunity for high-quality care at the end of life. The State Legislature should take steps to improve access to end-of-life/palliative care in healthcare institutions, hospices, home health agencies, and skilled nursing facilities.

Recommendations

1. Healthcare systems and the State of California should remove economic barriers by:
 - a. Removing the “reimbursement separation” for end-of-life care and integrate it into the current acute care payment system; and
 - b. Increasing research and training dollars in palliative and end-of-life care issues.
2. Healthcare systems and the State of California should remove barriers to excellence in care by:
 - a. Creating standards of palliative care for all healthcare systems, with penalties for those who do not meet those standards;
 - b. Allowing patients/families to transition to hospice services without having to give up disease-directed treatment before they are ready;
 - c. Developing quality indicators for symptom management, patient satisfaction, shared decision-making, coordination, and continuity for end-of-life care;
 - d. Developing a system that provides reliable data on the quality of life and quality of care of dying patients; and
 - e. Providing access in every healthcare system to properly trained specialists in palliative care.
3. Healthcare organizations should remove barriers to consumer education by:
 - a. Working to create a national database of resources for palliative and end-of-life care that may be accessed by the public; and
 - b. Affirming the integral role of family and friends in palliative/hospice care, providing caregivers with training and support in long-term home healthcare, and facilitating access to a greater range of options in respite care.

STATEMENTS ON PHYSICIAN-ASSISTED SUICIDE AND PHYSICIAN AID IN DYING

In addition to discussing and making recommendations on improving end-of-life care, participants also discussed the proper moral and legal status of physician-assisted suicide (PAS) and physician aid in dying (PAD). Although participants make no recommendation to the Select Committee on Palliative Care on this matter, participants believe that the dialogue itself was an opportunity for people—some representing institutions with strongly held positions—to engage one another in a respectful dialogue about an important, often contentious social policy question. Californians will and should continue to discuss this topic.

Below are two essays. The first presents arguments in favor of legalization. The second presents arguments in favor of current law, which prohibits PAS/D. All participants were invited to contribute points to each essay that support the respective arguments. Although only two essays are presented below, it is important to note that some participants do not fit clearly into either position; indeed some hold alternate positions.

ARGUMENTS IN FAVOR OF LEGALIZATION OF PHYSICIAN AID IN DYING IN LIMITED CIRCUMSTANCES

In the introduction to this document a case study was presented of a man dying of cancer. The case study was left open-ended. How did this patient actually die?

There are at least 4 possibilities:

1. He died a “good death” following excellent end-of-life care and experienced a peaceful ending.
2. End-of-life care reached its limit of controlling suffering — he (as an Oregon resident) had a “good death” through legal physician aid-in-dying (receiving a prescription to hasten death from a willing physician after going through a careful screening process).
3. End-of-life care reached its limit of controlling suffering – he (not being an Oregon resident)

received physician aid-in-dying from a physician in violation of state law. (We don't know whether it was a "good" or a "bad" death, because there is no record.)

4. End-of-life care reached its limit of controlling suffering — he (not an Oregon resident) had a "bad death" — either from untreatable suffering until death finally came — or by violent or other self-determined means by the patient with or without assistance of family.

Those who prepared this essay believe that the vast majority of terminally ill patients *do* or *could* fit into Category 1. We agree with all who shared in the preparation of this overall document: with high quality medical care, including good pain management and compassionate and competent palliative care, drawing on the best that caregivers, family members, spiritual leaders and others can offer, most patients, even when all hope of curing their terminal illness is gone, will experience a peaceful death that is free of unbearable suffering.

However, despite the very best medical care and the support of family members and the wider community, there is a small percentage of dying patients whose suffering, whether physical pain or other equally distressing psycho-social suffering, cannot be alleviated to their requirements. For some patients and families, even legal terminal (or total) sedation with withdrawal of nutrition/hydration is antithetical to their concept of death with dignity and subjects families to an extended period of grief and suffering.

For all these patients, Category 2, 3 or 4 above become the options.

Category 2 (legal physician aid-in-dying) is only available in the United States to residents of Oregon. Oregon is the only state which has a statute, enacted by an affirmative vote of 60% of its voters in 1997, making it legal for a competent, dying adult to request and receive physician aid-in-dying if that patient meets stringent legal requirements designed to prevent abuse of the law. It is significant to note, also, that since the implementation of this law, Oregon has the highest per capita use of hospice services, more persons dying at home and fewer in institutions, more milligrams of morphine per capita being used for pain management and more palliative-care and hospice-care teams within hospitals.

Category 3 (illegal physician aid-in-dying) happens in states other than Oregon. The extent of the practice is unknown, since it is difficult to gather data on an illegal practice. But substantial anecdotal evidence and several journal articles indicate that while the incidence of illegal assistance is not widespread, neither is it rare. Some argue that the decision should be left to individual

physicians and their patients and not be a matter of public policy. There are three problems with this position: 1) It makes a closet felon out of the physician, since she/he is knowingly breaking the law in providing assistance; 2) It makes scrutiny (oversight and controls) of the practice impossible, since it happens in secret; and 3) It makes the action of the physician, highly principled and compassionate or not, a paternalistic act, since discretion is in the hands of the physician alone.

Category 4 deaths (a bad death either from untreatable suffering or from desperate acts by patients or family members to end the patient's misery) are all too common horror stories. These tragic and often violent ends occur in large part because no compassionate physician is able to help. Two personal anecdotes, of hundreds that could be reported, were shared by members of the group. One told of her 93-year-old aunt, a talented artist, who was suffering greatly at the end of life after a major stroke. Having lost mobility and most speech, unable to move her tongue, she was confined to a nursing home, unable to live the life she had known, but not quite able to die. Her desperate plea was, "I'm suffering terribly; please help me to die." Neither her niece nor her doctor could respond to her request. The other incident, reported by a member who is a minister, was of a man in the late stages of terminal emphysema. Desperate, he waited until family members left the house and shot himself in the head. Were physician aid-in-dying legal, neither of these lives needed to have ended as they did. The recent double suicide of Admiral Chester Nimitz and his wife is another example of what happens when people do not see another way out.

Proponents of legalization of physician aid-in-dying argue that a legal right should be established which would permit, in carefully controlled circumstances and as a last resort, a competent, terminally ill adult to request and receive a physician prescription to hasten death when that patient deems further suffering to be unbearable.

Autonomy and the Common Good

Respect for autonomy and promotion of the common good are two key values in American culture and law. Sometimes, however, these are in potential conflict, and need to be balanced with each other. Maximum autonomy should be the birthright of anyone living in a free society. Autonomy must necessarily be constrained when its exercise would be hurtful to other persons. But our liberal democratic principles, informed by the writings of John Stuart Mill, stand for the proposition that the only legitimate constraints upon the liberty of the individual are those that are necessary to protect others from demonstrable harm. Physician aid-in-dying legislation, as proposed in a number of states and enacted in 1997 in Oregon, seeks a careful balance between individual autonomy and the common good.

In Oregon a full range of safeguards are in place:

- Physician aid-in-dying is patient driven. No one else can make this request on behalf of a patient. Only a willing physician will write the prescription.
- A patient to be qualified to receive physician aid-in-dying:
 - ◆ must be an adult resident of the state;
 - ◆ must be diagnosed as terminally ill by two concurring physicians competent to make such a determination;
 - ◆ must be judged to have decisional capacity by two physicians, subject to a mental health consultation if clinical depression is suspected (The critical question is, "Is the decision to hasten death the result of a treatable depression or the result of a rational process?");
 - ◆ must request medication voluntarily;
 - ◆ must make two oral requests to the physician, with at least a two week waiting period between requests;
 - ◆ must submit a written request witnessed by two persons, one of whom shall not be entitled to any portion of the patient's estate upon death;
 - ◆ may rescind the request at any time in any manner; and
 - ◆ must be informed of any other possible treatment options, such as hospice care and pain medication.

In addition:

- Without a terminal diagnosis, no person with a chronic illness or a disability is qualified for physician aid in dying.
- Physicians assess for presence of issues which may be coercive. Inducement or coercion of any patient to ask for physician aid-in-dying is a felony.
- Finally, the primary safeguard against abuse is the will to live. Only when suffering has become unbearable will a rational person seek a hastened death.

The Oregon experience, documented over four years, indicates that the common good and personal autonomy can work together. Just as with the policy to allow for the discontinuation of life support from both competent and incompetent patients, there cannot be a fail-safe system that eliminates any potential for abuse. But despite warnings of inevitable abuse and predictions of a slippery slope into coercion of vulnerable people to end their lives, there is no substantiated evidence of abuses or coerced deaths in Oregon. Nor is there evidence of financial savings being a motive for premature deaths (although the status quo elsewhere often does involve

over-treatment for financial reasons.) Grateful patients have been relieved to know that a peaceful release was available to them if they needed it.

One of our group members, an advocate for patients and families, while ambivalent about legalization, is an avid advocate of a patient's right to choice. After consultation with over 25 healthcare professionals, patients and loved ones, she reported their consensus, which included the statement that physician aid in dying is not a decision that anyone should or can make for another, only one that can be made by the sufferer. What is central is supporting patients' rights to make these difficult decisions for themselves when the time comes, as well as supporting families as they attempt to cope with their loved ones' choices.

Another member, a professor of biomedical ethics, wrote, "Some patients who refuse life-sustaining treatment have the intent of determining the timing and manner of their own death. If we are to consistently respect the wishes of dying patients on this critical issue, then physician aid-in-dying should be afforded (under constraints such as Oregon provides) without regard to whether or not the patient happens to be tethered to some form of life support."

Another of our members, a physician specializing in geriatrics, stated: "I have treated many hundreds of patients at the ends of their lives. I have heard these patients' sentiments about how they want to die. I have listened to their pleas for relief of suffering, and their wishes and hopes for a quiet, peaceful death.... With greater acceptance within medicine and society of the individual's right to self-determination, or autonomy, has come an increasing perception that this right should include the right to die. And should include the right to assistance in dying from medical professionals who can ensure that death comes as free of suffering as is possible.... For many of us, the right to a death free from suffering, under our own terms, represents the best hope for a peaceful end to our existence."

Two other members, a senior advocate and a physician who works with elderly patients, agreed that if after receiving palliative care, intractable suffering cannot be assuaged, the patient should have the option of choosing physician aid-in-dying.

Another group member, a social worker, summarized this way: "The common good would be enhanced by the dying person's realization that if suffering becomes unbearable it can be ended. If all of society knew there was a choice, the fear of dying could lessen, discrimination against the elderly could diminish and society would benefit."

The Role of Law

Some say that it is not the role of the government to be involved in the issue of physician aid-in-dying. But the government is already involved via laws in many states prohibiting assisted suicide, and in one state, Oregon, in permitting it in very limited circumstances. When the Supreme Court ruled on this issue in 1997, the decision of the Court strongly affirmed the proposition that it was and should be within the discretion of each sovereign state to determine its position on this important issue. Writing in a separate concurring opinion, Justice O'Connor specifically indicated that such matters were properly left for resolution in the "laboratory of the states," where a full and informed public dialogue could take place. If one of the roles of the law is to protect the common good without unduly restricting personal liberty, then to set strict standards permitting, but also carefully regulating physician aid-in-dying, does just that.

Suffering, Compassion and the Role of Physicians and Other Caregivers

A caregiver's role is to cure a patient if possible, and to palliate the patient's suffering if a cure is not possible. Suffering is not only physiological pain, but also psychosocial suffering in many forms. One member of our group, a nurse, emphasized the subjective nature of suffering: "An underlying assumption should be that suffering as perceived by the sufferer does not need to be proved."

A number of people come into hospice care wanting to end their lives. After all has been done to reduce suffering, the request usually goes away, *but not always*. What then?

Another member of the group, a physician who has been a hospice doctor, said, "This is about beneficence and non-malevolence, that is, doing good and not doing bad for a patient. If the very best end-of-life care does not deal with the patient's suffering, do I need to say 'You have to suffer; I can't help'? That doesn't meet the highest medical standards. It is a violation of the Hippocratic dictum, 'Do no harm.' If you leave a patient in that situation, you are doing harm to that patient as she or he defines it." It is abandonment of the patient when the patient's suffering can no longer be addressed. Therefore, physician aid-in-dying at a patient's request is viewed by many physicians as a rare action at the far end of a continuum of care. It becomes the willing physician's compassionate role to assist because the physician is the gatekeeper to the medication which can allow the patient to die peacefully when the burdens of continued existence, even with the best palliative medicine has to offer, significantly outweigh the benefits.



Morality

People of all faith communities (or none) agree with the affirmation of the sanctity of human life. Many also believe that at the end of life when intractable suffering can no longer be assuaged, a competent, dying adult should have a legal right to choose a hastened death with the assistance of a willing physician. In religious terms, this is an issue of free will and compassion. This is not "suicide" as this pejorative word is generally construed. Suicide is usually a tragic, isolated, often violent act of a depressed person whose life could go on with new hope. Physician aid-in-dying is the choice for a carefully safeguarded, peaceful end of a life which is already in the process of ending. Poll results consistently reveal that a significant majority of persons from most faith communities think this choice should be legal. Enlightened public policy is inconsistent with a blanket prohibition of physician aid-in-dying when the medical profession and society as a whole are seriously divided. In such situations, the matter should remain one of personal and professional conscience, constrained only by legislation that provides reasonable protection against the abuse of vulnerable patients. Current law, by prohibiting physician aid-in-dying, favors those who believe it is immoral. Legalization would give equal (not preferential) treatment to those who believe physician aid-in-dying can be a principled moral choice.

In Conclusion

One member, an ethicist who struggled with his position, finally wrote, "Human suffering does not admit of easy or risk-free solutions. It poses pressing and awesome challenges to efforts to alleviate it. Suffering is a multifaceted reality and addressing it is conceptually and existentially more complex than simply addressing pain. Suffering may pose such a horrifying burden on the one suffering that for that person death may seem a higher value than the maintenance of life."

"Physician aid-in-dying may thus be a necessary 'last resort' measure to address the suffering of another, not in place of but as one option within an array of needed palliative measures."

ARGUMENTS IN FAVOR OF CURRENT LAW AND AGAINST THE LEGALIZATION OF PHYSICIAN-ASSISTED SUICIDE

Introduction

The debate over legalizing “physician-assisted suicide” (PAS) is emotional and challenging. It takes us to the center of our culture and forces us to explore our basic values, our relationships and our spirituality. Our mediated dialogue involved conversations around the topics of suffering and compassion; autonomy and the common good; the nature and goals of medicine; safeguards, financial considerations and the vulnerable; and the law and public policy. We present these reflections for your consideration.

Suffering and Compassion

The average American is isolated from, and has a dramatic misunderstanding of, the dying process. The nationwide phenomenon of nursing-home neglect (particularly documented in California) is testament of not only a cultural isolation from illness, but also a concerted avoidance of the terminally or chronically ill. This isolation has given rise to widespread ignorance of the emotions that surround suffering. “Compassion” literally means, ‘to bear another’s suffering.’ Assisted suicide is not an appropriate response to dealing with these emotions as it eliminates suffering, not through treating the illness or emotions, but only by eliminating the sufferer. It does not get to the real issues. Understanding and dealing with the underlying suffering, while more demanding of the caretaker, has always been the hallmark of a compassionate society. This practice has also allowed protection from a “utilitarian” view of medicine and exploitation of the vulnerable.

Suffering encompasses more than pain. In particular, the suffering of the dying is most often spiritual suffering—angst, despair and hopelessness—and remains the most common reason for PAS requests. On the other hand, pain is the least problematic issue because in almost all cases, proper medication can achieve excellent pain control. We note that in Oregon, where PAS is legal under the “Death with Dignity Act” (DDA), virtually none of those who availed themselves of the law did so for intractable pain. Further, we assert that no empirical evidence suggests that pain is the primary reason for requests for PAS.

Secondly, suffering is often a consequence of poor medical and social services and of societal attitudes towards people with disabilities and people who are dying. Legalizing PAS will do nothing to address these problems and might well distract attention from them.

Compassion should never encompass ending suffering of others by ending their lives. In addition, engaging in PAS will take physicians into the realm of counter-transference: acting out their own needs at the expense of their patients. It is not, nor ever can be, competent end-of-life care.

Autonomy and the Common Good

The ethic of autonomy is an imperfect model for analyzing this issue. The Declaration of Independence asserts three inalienable rights: life, liberty, and the pursuit of happiness. These rights are elements of autonomy, but they are not absolute rights because they are in tension with the common good, as well as the other competing rights of the individual. For instance, there is no right to sell oneself into slavery even if it is self-imposed and freely chosen. That is because such an action violates all the other rights of the agent-victim. Likewise, PAS, through the destruction of the individual, violates both the rights of the person requesting it and the common good.

“Physician-assisted suicide” by its very definition is not an autonomous act. While individuals are free to end their own lives, the state has a strong interest in preserving life and preventing exploitation and harm in conduct between individuals. Autonomy does not trump state interests in protecting vulnerable members of society from their own decisions. Suicide is not victimless either with respect to the one that commits it or to others who witness it.

Legalization of PAS will necessarily place vulnerable patients in the hands of physicians that, through the intervention of lethal means, are thereby undermining not only the concomitant rights of the patient but other strategies to comfort them in their suffering.



The Nature and Goals of Medicine

Since the time of Hippocrates medicine has stopped short of causing intentional harm. Medicine, defined by common understanding of the principles of beneficence and benevolence, is separated by a bright line from harm done either for the perceived "greater good," the State, or for personal gain. These principles protect both the public and the profession. Physicians must not be put in the position of making judgments outside the domain of their professional expertise. Determining who ought to be candidates for death and who ought not to be is one such judgment.

In the world of legalized PAS, standards of quality assurance will become an absurdity, actionable torts will proliferate, and physician's standards will be skewed. This is all a dark domain that medical practice should not enter. Physicians should go to the bedside of the dying with compassion and understanding, including an acceptance of their own limitations. The prescription of lethal drugs is outside of and not a part of a continuum of end-of-life care.

Despite attempts by advocates to change the language from "assisted suicide" to "aid in dying," what is being described is the same: the act of self-killing with outside assistance. Mental health experts have long held that the desire for suicide is an illness, with the same root causes in all circumstances. It is contradictory to the standards of medical practice to carve out a special class of suicidal patients, i.e., the terminally ill, and suspend the rules.

In fact, by so doing, it will be affirmed that the terminally ill are in a marginal state of being, presumed to be unworthy of life. When dying patients crave death it is often a transient episode of depression that can be easily resolved. Deconstructing the medical meaning of suicide is dubious, but making it a medical treatment is incongruous. Moreover, death cannot be redefined as a legitimate medical treatment, accompanied by a discussion of risks and benefits.

Causing death remains the worst harm. Knowingly causing harm doesn't fit inside the medical model. It is facile to redefine a "competently requested" death as harmless.



Depression fits imperfectly in medical practice in large part because the patient can seem highly rational, yet relentlessly committed to self-destruction. It is a source of extreme suffering for those afflicted by it and seems a reasonable explanation for most of the "assisted suicides" that occurred in Oregon. It remains poorly understood and poorly managed. Changing the meaning of suicide cannot improve this situation. Depression should be treated. It is a *non sequitur* to consider whether a disease is rational; the disease itself challenges our sense of meaning. But its therapy should be rational. In addition, terminal illness, itself, remains a vague concept.

Experienced physicians cannot accurately predict death more than a few weeks in advance. Also, they tend to be optimistic, wishing to preserve hope. Most Americans die of diseases without a defined "terminal" course (heart disease). In retrospect, many terminally ill patients are indistinguishable from healthy people until weeks before death; they are not discomfited or disabled by their disease.

On the other hand, when death is near patients usually die. Few physicians withhold aggressive palliative measures, including controlled sedation, from those that are imminently dying and suffering noxious symptoms. Thus, the need for "assisted suicide" remains questionable. The ethical doctrine of double effect allows vigorous treatment that might shorten life. Physicians may engage in the medical action termed "terminal sedation" under certain circumstances:

1. Death is imminent. (Days, not weeks or months).
2. There are intractable symptoms for which medication offers legitimate benefit. (Terminal delirium)
3. The intent is not to kill.
4. Lethal medications are not given (paralytic agents, bolus potassium).
5. The withdrawal of hydration must not be presumed but occurs only by patient request.

The continuum of medicine must stop short of causing intentional harm. Nothing within the parameters of medicine or training of physicians qualifies them to render judgments about whether patients are making a "valid" request for a lethal prescription. Most mentally ill patients are competent, so competency is the wrong question. Moreover, because many physicians lack skills in pain management, end-of-life care, and psychiatric assessment, the ancient prohibition against doing harm remains the best protection against exploitation and incompetent medical practice.

Safeguards, Financial Considerations and Vulnerable Patients

Legalized PAS makes physicians, who have no expertise in these matters, the societal gatekeepers to prevent coercion, exploitation, and other forms of misconduct. In addition, those seeking PAS will be attracted to physicians who believe such actions are legitimate, and treatment of the underlying causes of the suicide request may remain untreated. If “death with dignity” is cheap and easy, why expend resources on those who no longer contribute to society? Why even have hospices if people can instantly end their suffering with a lethal overdose?

Research overwhelmingly shows that people with new disabilities frequently go through initial despondency and suicidal feelings, but later adapt well and find great satisfaction in their lives. However, the adaptation usually takes considerably longer than a two-week waiting period required by PAS proposals and Oregon’s DDA. People with terminal illness appear to go through similar stages of grief. In that early period before one learns the truth about how good one’s quality of life can be, it will be all too easy to make the final choice - one that is irrevocable.



Hopelessness about the future seems a common thread in those that make requests for PAS. It reflects family conflicts, unresolved spiritual issues, fear of “becoming a burden,” and many other problems, which eventuate in depression with suicidal thinking. These psychosocio-spiritual crises are amenable to simple interventions if a lethal prescription is not an option. The presence of that option will ultimately become obligation.

The presumption that safeguards will weed out illegitimate requests and force the individual desiring assisted suicide to have exhausted other remedies has been proved false. It is fanciful to assume that there is a reliable way to know whether a person has “real” intractable suffering and that the choice of PAS was a “last resort.” The data from Oregon suggest otherwise, that those using the DDA are mostly elderly cancer patients who have neither pain nor disability, but were fearful of what might happen to them—the loss of independence and bodily integrity. It is hard to believe that these circumstances represent a “last resort.” In the Netherlands both current practice and case law have stripped away the presumed safeguards.

Proposed safeguards are viewed as highly intrusive on medical practice, hence their lack of application in Oregon and the Netherlands. External supervision cannot easily distinguish between vigorous palliative care and euthanasia. Disingenuous enforcement of safeguards is tantamount to no enforcement at all.

Ironically there is one strong safeguard in most “assisted suicide” proposals—a safeguard, not for patients, but for HMOs and doctors: the “good faith” standard. This “safeguard” provides that no person will be subject to any form of legal liability if they claim that they acted in “good faith.” A claimed “good faith” belief that the requirements of the law are satisfied is virtually impossible to disprove, rendering all other proposed “safeguards” effectively unenforceable.

Perhaps the most significant problem with legalization of PAS is the deadly mix between “assisted suicide” and profit-driven managed health care. The cost of the lethal pharmaceuticals used for “assisted suicide” is about \$35 to \$50—far cheaper than the cost of treatment for most long-term medical conditions. The drive to save money by denying treatment is already a significant danger; it will be far greater if PAS were legal. Pressures to forgo expensive, marginal interventions will mount. The availability of PAS will accelerate the decline in the quality of our healthcare system.

The impact will be deadly for the socially and economically disadvantaged groups who have less access to medical resources and who already find themselves discriminated against by the healthcare system. Poor people, elderly people, people with chronic or progressive conditions or disabilities and anyone who is, in fact, terminally ill will be put at serious risk. Leaders and researchers in the black and Latino communities have stated their fears that pressures to choose death will be applied disproportionately to their communities.

Law and Public Policy

Finally, legalizing assisted suicide will have profound public policy implications. Changing the traditional parameters of medical practice will damage the common good by removing a protective boundary from a vital profession and exposing vulnerable populations to an expectation that they avail themselves of PAS rather than become a burden on society or their families.

There is no moral distinction between a physician's sponsoring an overdose and injecting lethal drugs. Legalization of PAS renders laws against other forms of euthanasia unenforceable and assures adoption of directly administered euthanasia, as it is a more reliable way of ending lives.*

Clearly, the state has an interest in protecting the public and regulating the conduct of licensed professionals. While suicide cannot be prohibited, it should not be sanctioned. Once PAS has been accepted for one class of citizens it cannot be contained. Once it becomes

*Assisted suicide proponents and medical personnel alike have documented how taking lethal drugs by mouth is often ineffective in fulfilling its intended purpose. The body expels the drugs by vomiting, or the person falls into a lengthy state of unconsciousness rather than dying promptly, as PAS supporters wish. Such ineffective suicide attempts happen in a substantial percentage of cases—ranging from 15% to 25%. The way to prevent these “problems,” in the view of euthanasia advocates, is by legalizing lethal injections by doctors, which is active euthanasia.

accepted practice it will be wrong arbitrarily to exclude others. There are no compelling arguments that “terminal patients” are sufficiently different from the “un-terminal” to remain a restricted category. Creating an exception to the standards of medical practice for the dying assures that anyone with self-described, intractable suffering will qualify for “assisted suicide,” whether terminal, competent or adult. To do otherwise is prejudicial and unconstitutional.

Laws define the boundaries of our relationships with one another. They are the “rules” that clarify what we can and cannot do in our relationships with one another. Laws define normative behavior for our participation in society. Laws teach us what is minimally ethically acceptable. In a society that functions under the rule of law whatever is legal is assumed to be morally acceptable. Laws protect those who may be vulnerable to abuse by those who are more powerful or influential.

Public policy requires us to consider the common good, the social welfare above individuals' personal desires. Because public policy is the expression of our common values and beliefs, it should only be changed when it benefits the common good, and never be changed for the wishes of a few.

END NOTES

- i Right of Control laws refer to the statutes that guide funeral directors and others in the death care industry as they make decisions about the disposition of the body, etc.
- ii According to the California Department of Justice, in February 1999 there were 74,518 California-licensed physicians with Schedule II privileges, but only 40,333 (54 percent) had triplicates issued to them. A 1998 survey of 6,000 physicians found that 71 percent utilize drugs not requiring a triplicate form because of concern about regulatory scrutiny, even when a Schedule II drug is indicated. A 1993 study by Von Roenn, et. al. found that 79 percent of physicians surveyed cited excessive regulation and reluctance to prescribe as significant barriers to pain management.
- iii Controlled Substances Act – The group discussed the Federal Controlled Substances Act (CSA) and its relationship to pain management. The discussion did not yield a recommendation. The discussion centered on whether the CSA could have a limiting effect on pain management.
- iv Porter, J. and H. Jick. “Addiction Rare in Patients Treated with Narcotics.” *New England Journal of Medicine*. 1980. 320:123.
- v AB 487, Aroner: An act to amend Section 2313 of, and to add Sections 2190.5 and 2241.6 to, the Business and Professions Code, relating to medical practice. Chaptered in 2001.

Legislative Counsel's Digest:

“Existing law, the Medical Practice Act, provides for the regulation of physicians and surgeons by the Medical Board of California. Under that act, the board's Division of Licensing is required to adopt and administer standards for the continuing education of physicians and surgeons, and the board's Division of Medical Quality is required to take disciplinary action against those who are charged with committing unprofessional conduct and to report annually to the Legislature regarding those actions.

“This bill would require the Division of Medical Quality to develop standards before June 1, 2002, for the investigation of complaints concerning the management, including, but not limited to, undertreatment, undermedication, and medication of pain and to include in its annual report to the Legislature a description of actions relating to that practice. The bill would also require physicians and surgeons to complete a mandatory continuing education course in the subjects of pain management and the treatment of terminally ill and dying patients by December 31, 2006, except that it would not apply to physicians practicing in pathology or radiology specialty areas. The bill would authorize the board to adopt regulations exempting physicians who do not engage in direct patient care, do not provide patient consultations, or do not reside in California.”

vi See footnote 5.

vii AB 791, Thomson: An act to amend Section 2089 of the Business and Professions Code, to add Section 1254.7 to the Health and Safety Code, relating to the healing arts. Chaptered in 1999.

Legislative Counsel's Digest:

“Existing law regulates the practice of medicine, and sets forth curriculum requirements for all applicants for a physician's and surgeon's license. This bill would add pain management and end-of-life care to the curriculum requirements for persons entering medical school on or after June 1, 2000.

“Existing law provides for the licensure and regulation of health facilities by the State Department of Health Services. Under existing law, violation of these provisions is a misdemeanor. This bill would require every health facility licensed pursuant to these provisions, as a condition of licensure, to include pain as an item to be assessed at the same time as vital signs are taken. By changing the definition of a crime, this bill would impose a state-mandated local program.”

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