Legalizing Assisted Death (AD): compassion and profession in conflict

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Deconstructing the question of legalization...

• An individual's liberty right to take his/her own life (2 slides)
• The physicians (team's) caring role
• Society's role in supporting both
• The Profession's role in responding
• Organized Medicine's role in guiding

Legalized AD: Ethical Arguments Pro / Con

• Pro
  • Patient's right to choose (autonomy)
  • Physician's primary obligation to care for and respect their patients (compassion, beneficence)
  • Obligations to offer reasonable and morally acceptable standards of care within legal constructs
  • Medicine's longstanding tradition of offering care for the frail, sick and suffering
  • Decreases cost and burden to others

• Con
  • Endangers and disenfranchises the weak and vulnerable
  • Neglects other forms of 'intolerable suffering'
  • Corrupts the practice of medicine (fundamentally inconsistent with the role of physicians as healers)
  • Destroys doctor-patient relationship...
  • Mobilizes trust
  • Congressional (compassionate "nudging") is inevitable
  • May compromise the family and intergenerational commitments...
  • Duties to die
  • Detracts from needed policy and practices to improve EOL care and treatment
  • Betrays intrinsic human dignity and equality
Equating Rights to Abortion (AB) and PAS

• AB is a “privacy” (autonomy) argument – when the life and/or welfare of one person is negatively impacted by the inextricable presence of another, there is an autonomous right to be free from that intrusion, especially if it is potentially dangerous or harmful (tubal pregnancy). Altruism, though encouraged, is trumped by the person’s right to privacy and protection.

• AD is a “right of equal protection” argument (14th amendment) – though individuals arguably have the right to kill themselves, there is not a similarly ascribed right to assisted death as a means of protection (from unwanted suffering).

Broader Questions about the Ethics of AD

• The ethical analysis is complex, emotionally laden, and often results in conflict
  • Is it ethical or unethical to (or not to) offer AD to suffering and dying patients?

• The narrower context of care (bedside)
  • All HC professionals share a commitment to improving the plight of suffering patients.

• The broader context of care (population health)
  • There is legitimate concern about unintended consequences when framing health policy, developing standards of care, deploying resources, discrimination, and harming the most vulnerable.

• As members of the medical community physicians have a collective obligation to both care for and protect patients and ensure professional integrity.

• As colleagues and members of the healing profession we must find a way to accommodate our differences for the greater good.

The Ethical Debate about legalizing and practicing AD

Pro

Compassion

Patient Welfare

Where come together...

Con
History and Tradition of Suicide

- Ceremonial suicides in the Aztecs and Incas
- Hindu, Buddhism, and Shinto allow suttee and hara-kiri
- Romans and Greeks relaxed attitude toward suicide – Cleopatra/Mark Antony
- Neither the Bible (N 7) nor Koran explicitly condemn, though mercy is praised ("Blessed are the merciful...")
- Condemned in Middle Ages - "illegal" → a sin associated with "damnation"
- 19th century shift from "sin" to "insanity"... not "illegal" in 20th century
- Military Hx – Masada (74 CE), kamikaze pilots, suicide bombings, suicide pills
- Hx in social protest – slaves, Thích Quảng Đức (S. Vietnam), cultural revolution
- Existential underpinnings – van Gogh

Moral permissibility of Suicide

- Aristotle condemned; Plato ambivalent – except in hopeless cases
- Seneca - "eternal law" offers "freedom" to choose means of death
- Aquinas condemned - injures others and the community and violates God's authority over life (God's gift)
- deMontaigne - "personal choice" and acceptable in some cases (pain and suffering)
- Hume - morally permissible if "good" for the individual outweighs the loss to society
- Locke and Kant opposed - life is an inalienable right and obligation; forbidden rational moral responsibility to live and contribute
- Mill opposed - rejects acts that remove possibility of future autonomous decisions
- Present day: divided opinion on U.S. laws against but patients who survive attempts are "detained" (96° hold) until mental illness is ruled out

Assisted Suicide (AD): Competing Obligations when a request is made

- Physicians – must respect patients’ wishes to the extent possible, comply with practice standards, ensure fair and compassionate care, and advocate for patients at many levels
- The Profession (organizations) – must ensure professional competence of members, encourage collaboration, and support members’ efforts to provide equitable and safe care, recognizing there are multidimensional perspectives and variable legal frameworks of practice; also to advocate for vulnerable and disenfranchised patients
- Society – must ensure access to fair and safe practices for all who live within its borders
Arguments offer many levels of moral conflict/ethical disagreement

- Professional obligation to do good and not harm (Hippocratic Oath and Corpus 400 BC; AMA 1994)
- Professional obligation to offer a “merciful release from incurable sufferings” (Joseph Fletcher, Morals and Medecine, 1954)
- Personal right to choose how and when we die (autonomy and dignity arguments)
- Personal “positive autonomy” right to death services (snuck down by NY Courts: twisted)
- Potential harm to those who may not be able to speak or act for themselves...the unconscious, elderly, children, disabled, poor, minorities (individual fairness and distributive justice)
- Fair access to AD for those without access to healthcare or who do not “qualify” (individual fairness and distributive justice)
- Potential for abuse and erosion of trust in response to financial concerns or feeling of being a burden to others (maximizing utility)

T. Quill

- Advocates for a balanced approach to developing policies, practices, and legalization of AD
- Legal palliative care options, including AD if requested, should be available to suffering and dying patients.
- Encourages greater efforts in ensuring good palliative care and a “stance of studied neutrality” by physician organizations (like ACP and AMA) to encourage dialogue about guidelines and policy development that will improve EOL care

Paul Ramsey – ambiguous?

Encourages acceptance to relieve personal suffering “beyond our love and care.”


Also claims it is incompatible with the obligation of covenantal fidelity and the imperative to never abandon care.

“God's steadfast covenantal love is the standard by which we demonstrate fidelity to one another. Therefore, to hasten the death of a dying patient is to abandon care and thus contrary to the obligation of charity and fidelity.”

E.D. Pellegrino - not ambiguous!

- Beneficence of AD is "illusory"
  - Influence of cost containment (high value care)
  - Coercion by physicians and insurance companies inevitable
  - Erosion of trust and confidence in physicians and HC systems
  - Diversion from other standards of care
- Palliative Care can be highly effective when utilized appropriately
- Devalues the lives of the elderly, disabled, and chronically ill
- Desensitizes physicians and society
- Distorts the idea of compassion and altruism
- Deviates energy, efforts, and resources away from policies and practices to relieve suffering


E. Emanuel

- AD in the form of PAS will "almost certainly" extend to voluntary euthanasia.
  - (In the Netherlands) the persistence of abuse and the violation of safeguards, despite publicity and condemnation, suggest that feared consequences of legalization are exactly its inherent consequences.
  - The logic of understanding voluntary euthanasia as "healing" begins to justify using it for children, the incompetent, the mentally ill, and others who are suffering or who we imagine are suffering.
- For every (cancer) patient who is likely to be reassured by a discussion of PAS or euthanasia, another finds that such a discussion would decrease patients' trust in the care being provided.
- Broad legalization of PAS would have the paradoxical effect of making patients feel responsible for their own suffering.
  - Once routine, over time, doctors will become comfortable using it as a standard of care.
- Keep it illegal but for "exceptions" (unspecified).

Emanuel E. Whose Right to Die? The Atlantic. March 1997

E. Emanuel

- Survey in 2000 (n=988): 60% terminally ill patients support AD but only 10% seriously considered it for themselves — half changed their minds after a few months (both ways) if depressed more likely to consider AD at later date
  - Those more likely - depression, high caring needs, pain
  - Those less likely - feeling appreciated, >65yr, AA
- No compelling evidence that legalizing AD in the US would improve EOL Care. Diverting resources may impair, not improve, care at EOL.
- Risks of harm - undermines medical profession; undue anxiety; coercion unavoidable; premature death; ultimate use in incompetent patients; increase family suffering.
  - Cost savings not a legitimate argument:
    - estimated at $527 M in 1998 (<0.07% total HC expenditures).
    - ave amount of life forgone in patients choosing AD = ~4 weeks

Emanuel E, Fairchild D, Emanuel L. Attitudes and Desires Related to Euthanasia and Physician Assisted Suicide Among Terminally Ill Patients and Their Caregivers. JAMA. 2000;284(19):2460-2468

Emanuel E. What is the Great Benefit of Legalizing Euthanasia or Physician Assisted Suicide? Ethics. 1999;109:629-642

Emanuel E and Battin M. What are the Potential Cost Savings from Legalizing Physician Assisted Suicide? NEM. 1998;167:1-12
D. Callahan

- Personal good inextricably linked to the “public good” – collective welfare
- Suicide a public health crisis in U.S. - 43,000 a year, 24% increase 1999-2014
- Striking conflict between efforts to both prevent suicide and legalize AD in Oregon and Washington
- AD not considered “suicide” thus not counted in annual suicide totals
- Increase in overall suicide rate parallels the increase in AD — “Werther Effect”
  - 2015 study: legalizing AD in Washington State à 6.3% increase in total suicides
- Response to the existential argument à “inherent dignity cannot be lost”
- “Exaltation of autonomy” à expansion of patient expectation and calls for loosening criteria (“those who have lived long enough”, burden to others, ageism)


B Steinbock and Y Kamisar

- Consequentialist approach – failure to consider the social consequences of legalizing AD
  - Terminal illness
  - Inability to relieve intolerable pain and suffering
  - Unwarranted and irrational desire to die
  - 6 month prognosis
- Appeal to dignity...what is it to “die with dignity”? 
  - vague, perhaps objectionable (discriminatory?) toward the disabled
  - suggests it is lost with impairment or dependence on technology...but how?
- Some may feel pressured to choose death because of financial concerns or difficulty in finding care support:
  - Poor, elderly, disabled, minorities, unassertive, chronically depressed, women
- Anecdotal cases of family coercion and participation, treatable depression


The Social Experiments: Netherlands

- Assisted suicide: Canada, Netherlands, Luxembourg, Switzerland (1949), 6 states / DC in U.S.
- Netherlands 1990 to 2015 à the numbers are up!
  - Presently, 4.5% of all deaths are due to euthanasia (nearly 1 in 20) - up from 1.7%
  - most Dx = cancer, heart, lung, neurological disease
  - also nonterminal illness: deafness, blindness, tintnus, depression, dementia
  - 55% decisions preceding death rose from 38% to 58%
  - without consent dropped from 0.8% to 0.3%
  - for existential suffering (not “terminal”) trend of living, lonely, psychological
  - for psychiatric disorders mostly women with complex histories — eligibility disagreements common
  - non-voluntary euthanasia – children, infants, elderly, demented, and mentally ill
  - by doctor's request from 10% to 30%
  - by continuous deep sedation rise from 8.2% to 18.3%
  - over 80 yr rose from 22% to 35%
- 2005 (NEJM) 122 infant euthanasia deaths in previous 7 years
- 2013: 1243 infants per year eligible for euthanasia

Van der Heide A, van Delden J, Onwuteaka-Philipsen B. End of Life Decision in the Netherlands over 25 years. NEJM. 2017;377(5):494-496

For the latest news please visit: Euthanasie Studies Towards a Better Decision / M. W. J. van der Heide et al. in Netherlands over 15 years. Kluwer. 2013:11111-11115
Belgium

- In 2010, 66 of 208 euthanasia deaths without explicit patient request
- AD deaths rose from 2% in 2007 to 5% in 2013; approvals increased from 55% to 77%
- 2014 law allowed euthanasia of “consenting minor”
- Concerns:
  - Not transparent—relies on a 16 member euthanasia commission for oversight
  - Relies on self-reporting—many may go unreported
  - Little opposition to the continuing expansion of AD
  - AD has been “normalized” in practice and society
  - “Once legal, AD tends to develop a dynamic of its own and extend beyond agreed restrictions.”
  - Little has been discussed about the end of AD

Concerns:

- No safeguards to ensure capacity (5/178 who died from PAS 2013-14 referred for psychiatric evaluation)
- Physicians immunized from prosecution, liability, or professional discipline
- When Rx administered no safeguards to ensure voluntariness or capacity, or to guard against coercion
- Financial incentives for families and insurance companies (see cases)
- Dr. or RN often not present at time of death

Organ donation after euthanasia now allowed in Belgium and Netherlands

- Estimated that 10% of patients being euthanized could donate at least one organ
- “Could potentially help reduce the wait list.”
- 43 have donated in Belgium as of August 2016

PAS in the US

- Since 1994, over 140 legislative proposals in 27 states to legal Oregon-style laws
- In 2015, 18 states and DC considered laws allowing PAS
- Oregon Death with Dignity Act, 1997:
  - Motivation for request: 91% loss of autonomy, 71% loss of dignity, 31% inadequate pain control
- Concerns:
  - No safeguards to ensure capacity (5/178 who died from PAS 2013-14 referred for psychiatric evaluation)
  - Physicians immunized from prosecution, liability, or professional discipline
  - When Rx administered no safeguards to ensure voluntariness or capacity, or to guard against coercion
  - Financial incentives for families and insurance companies (see cases)
  - Dr. or RN often not present at time of death

US jurisdictions where PAS is legal

DWDA Requirements (Oregon)

- The requesting patient must be:
  - An adult (18 years of age or older)
  - A resident of Oregon
  - Capable (defined as able to make and communicate health care decisions)
  - Diagnosed with a terminal illness that will lead to death within six months
- Those meeting these requirements are eligible to request a prescription for lethal medication from a licensed Oregon physician.
- To receive a prescription for lethal medication:
  - The patient must make two oral requests to their physician separated by at least 15 days.
  - The prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
  - The prescribing physician and a consulting physician must determine whether the patient is capable.
  - If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder, the patient must be referred for a psychiatric or psychological examination.
  - The prescribing physician must inform the patient of feasible alternatives to AD, including comfort care, religious care, and pain control.
  - The prescribing physician must request, but may not require, the patient to notify his or her next of kin of this prescription request.

https://public.health.oregon.gov/Provider-PartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ors.aspx
Oregon’s 20 year Experience with PAS

- 0.2% of annual deaths attributed to PAS (N 991)
- 14% increase from 1998-2013
- 36% increase annually from 2013-2015
- 97% requesting were white, 72% had some college, 51% were men
- 1 African American
- 1.4% (N 13) uninsured (41% MC/MC)
- Median age 71yo (76yo overall) – 70% > 65yo
- Reasons for request:
  - 91% loss of autonomy
  - 89% loss of ability to participate in enjoyable activities
  - 20% pain
  - 4% financial
- Concerns:
  - Psychological referrals infrequent – in 2014 only 2 of 105 who died due to AD referred for eval.
  - Many patients do not have a long standing relationship with the physician providing the service
  - Underreporting
  - Not following standard protocol
- EOL care is exceptionally good in Oregon (90% of PAS deaths enrolled in Hospice)

Impact on Trust


- 1117 U.S. adults were asked to respond to the question: “Legalizing AD will lower trust in your doctor.”
- Overall 58% disagreed - 20% agreed
  - 64% highly ed., 48% earned over $40K/yr., 83% white, 10% black, 68% F, mean age 49 yo
  - 27% elderly agreed
  - 32% blacks agreed
  - Level of disagreement:
    - Increased with income and education level
    - Decreased with level of physical and mental health
  - Views correlated with underlying trust in the physician and satisfaction with care.

Public Opinion: Pew Research Center, November 2013

“Views on End-of-Life Medical Treatments”

- There are some situations in which a patient should be allowed to die: 66%
- Made written or verbal HCD: 35%
- Moral right to suicide if suffering and no hope of improvement: 62%
  - Along lines of religious belief (range = 42% black Prot. - 71% white Prot. - 85% unaffiliated)
- Moral right to suicide if “ready to die because living is a burden” (38%) or “burden to family” (32%)
- Legalizing PAS for the terminally ill: 47% approve, 49% disapprove
  - Approval: Whites 53%
  - Disapproval: Blacks 65% (black Prot. 72%); Hispanic 65% (Hisp Cath 63%)
- Gallup Poll 2013 (moral acceptability of PAS): 45% yes, 49% no
- If incurable disease and suffering:
  - Allow death to occur - 65% of whites
  - “Do everything” - 55% of Hispanics and 61% of blacks; 71% if 65-74yo; 62% if > 75yo
Concerns of the Disabled

Many Disability Groups Oppose AD Laws

- ADAPT (American Disabled for Attendant Programs Today)
- American Association of People with Disabilities
- Assn of Programs for Rural Independent Living
- Autistic Self Advocacy Network
- Disability Rights Center & Road to Freedom Bus Tour
- Disability Rights Education and Defense Fund
- National Council on Disability
- National Council on Independent Living
- National Organization of Nurses with Disabilities
- National Spinal Cord Injury Association
- Not Dead Yet
- TASH
- The Arc of the United States
- United Spinal Association

While some seek AD through legal protection from the courts

September 14, 2017

NY Court of Appeals unanimously dismissed a case initiated in 2015 by three terminally ill patients requesting the legal right to receive the lethal medications from their doctors.

"No fundamental constitutional right to... also reject the assertion that the State's prohibition on assisted suicide is not rationally related to legitimate state interests."

Nat’l Council on Disability’s concern about disparities

"Current evidence indicates clearly that the interests of the few people who would benefit from legalizing physician assisted suicide are heavily outweighed by the probability that new procedures and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities. At least until such time as our society provides a comprehensive, fully-funded and operational system of assistive living services for people with disabilities, this is the only position that the National Council on Disability can, in good conscience, support.

NCD Letter to AMA 2-15-17

"Physician assisted suicide disproportionately harms people with disabilities, the elderly, and people who are poor and opens the door for insurance companies to provide PAS in lieu of costly treatment options."

"... without the means to live, the “right-to-die” becomes the dangerous default."
### Attitudes of Physicians

  - Scenario: 72yo man in Oregon with metastatic pancreatic CA contemplating PAS
  - 74 countries, 2356 votes
  - 65% overall voted against PAS
  - 67% U.S. Physicians voted against PAS
  - Concerns expressed (against): violates physician’s oath, slippery slope to euthanasia
  - Concerns expressed (for): honoring pt. autonomy, if assist birth should also assist death
  - All confirmed importance of good, universally accessible palliative care/hospice

  - 3102 physicians in 10 specialties, 61% response rate
  - 18% have received requests
  - 11% willing to give Rx; 38% willing if legal... 3.3% have done it
  - 7% would give lethal injection; 24% would give if legal... 4.7% have done it

### Oncologists (Ann Int Med Oct 3, 2000)

- 3299
  - 22.5% support use of PAS
  - 6.5% support euthanasia
  - 3.7% have euthanized
  - 10.8% have performed PAS
  - Those reluctant to increase narcotics and those self reporting adequate training in EOL care were less likely to perform EU or PAS

### Osteopathic physicians (JAOA 2002;102(1))

- 1028
  - 58% not willing to Rx for PAS
  - 55% oppose legalizing PAS
  - 33% received requests
  - Influence on response: osteopathic principle of "holistic care (53%), oath (44%), religion and degree of prayer"

### Similar Slopes” embraced historically by society and the medical community

- T4 euthanasia program in Germany for mentally and physically handicapped (1939)—200,000 killed
- Euthanasia Society of America (1939) drafted proposed law permitting voluntary euthanasia
- Eugenics program in the U.S. 1920 – 1970
- Tuskegee Study of Untreated Syphilis in Negro Males 1932 – 1972
- Henrietta Lacks’ HeLa Cells 1951-1975
- Racial segregation in hospitals well into the 20th century
Cases - Anecdotal evidence

- 85 yo CA patient – questionable capacity, strongly influenced by family’s wishes, repeated consultations sought until approved. Financial considerations may have influenced decision (requirement for capacity)
- 43 yo with ALS—difficulty to swallow pills; brother in law “helped” him die at home (requirement to self-administer)
- Lung CA – treated for suicidal depression; died naturally two years after given first lethal Rx. (requirement for competency and 6 month prognosis)
- Lymphoma – PCP offered to write Rx for an “extra-large amount of pain medication”. Pt declined, lost trust in her physician (coercion)
- 78 yo p CVA – lethal injection given by her doctor when withdrawal of life supporting treatment failed (euthanasia illegal)

Cases

- Lung CA – took Rx, slept for 65 hours, then woke up (unsafe practice: in Netherlands 18-25% who take same Rx and dose do not die)
- Breast CA – pt. eager to die but did not meet criteria – a third physician gave Rx (requirement for 6 month prognosis)
- 71 yo with ALS – did not meet 6 mo. criteria but oncologist gave Rx, which she couldn’t take; two sons spooned it into her mouth (requirement for 6 mo. prognosis)
- 76 yo physician with malignant melanoma – depressed. PCP refused to be the second physician to confirm prognosis and request. A third physician was found to confirm but the patient was not referred back to his PCP, preventing him from participating in his patient’s EOL care. (unprofessionalism)

Insurance companies denied treatment to patients, offered to pay for assisted suicide, doctor claims

- Nevada internist seeking approval for two patients to receive life saving treatment in California and Oregon was told by two insurance companies, “...we’re not going to cover that procedure or the transfer, but would you consider assisted suicide?”
- In 2008, a 64 yo patient received a letter from state’s Medicaid program declining to cover lung cancer treatment costing $4,000 per month. The Oregon Health Plan, however, did offer to pay for assisted suicide drugs costing $50.
Professional Medical Organizations

"Physician-assisted suicide is fundamentally inconsistent with the physician's professional role."

"Requests for physician-assisted suicide should be a signal to the physician that the patient's needs are unmet and further evaluation to identify the elements contributing to the patient's suffering is necessary."

"Absence of evidence is not evidence of absence of unintended consequences."

Professional Codes

- Hippocratic Ethos:
  "I will not give a lethal drug to anyone if I am asked, nor will I advise such a plan." (Oath)
  "...to lessen the violence of their disease and to refuse to treat those who are overmastered by their disease." (On the Art)
  "I will...help the sick according to my ability and judgement but never with a view to injury and wrong doing." (Oath)

- AMA Code of Ethics:
  "...fundamentally incompatible with the physician's role as a healer, would be difficult or impossible to control, and would pose serious societal risks.
  "...permitting physicians to engage in euthanasia (physician assisted suicide) would ultimately cause more harm than good...could also readily be extended to incompetent patients and other vulnerable populations."

  "The College does not support legalization of physician assisted suicide or euthanasia."
  "...might undermine patient trust; distract from rework in EOL care; and used in vulnerable patients, including those who are poor, are disabled, are unable to speak for themselves, or minority groups who have experienced discrimination."

Calls for a Neutral Stance ("moral equipoise")

The debate...

• “Studied and engaged neutrality is needed to ensure better communication, safety, and comfort.”
• To be more responsive to members in helping them minimize potential harms in states where AD is legalized is a “patient centered” approach

VS.

• Remaining “neutral” is contradictory to the physician’s role; trust is dependent on compassionate but objective and honest discussions about prognosis, standards of care, and what is most advisable for the patient
• Autonomy (“granting wishes”) alone offers a shallow definition of patient centered care that requires universal access to compassionate and reasonable treatment options and threatening to none.
• A position of “neutrality” is tantamount to acquiescence or perhaps acceptance of a practice that could be harmful or threatening to many in society, especially the most vulnerable.

ACP reaffirms professional responsibility to improve care for dying patients and their families. ACP does not support legalization of physician-assisted suicide (reaffirming the 2001 Position)

Those who do and do not lawfully participate should ensure that all patients can rely on high quality care through to the end of life.

ACP’s Position

• Obligation to ensure that all patients can rely on high quality care through to the end of life:
  • Prevention or relief of suffering where possible (not all suffering can be relieved)
  • Commitment to human dignity
  • Support families and loved ones
• Research suggests a slippery slope
• Ethical arguments against legalization of physician-assisted suicide remain the most compelling. We are mindful that ethics is not merely a matter for a vote.
• Majority support of a practice does not make it ethical.
• Medical history provides several cautionary examples of laws and practices in the United States (such as racial segregation of hospital wards) that were widely endorsed but very problematic.
The art and influence of “nudging”

“...clinicians are now in a position of heavily influencing the choices their patients and family members will make. The task of the conscientious clinician isn’t to avoid influencing choices, but rather to avoid restricting choices. And better to influence choice mindfully in a way that likely promotes good outcomes for your patients than to continue doing so haphazardly.”

Dr. Scott Halpern
critical care physician
U Penn

Remember the Unintended Consequences

- When PAS is legal and professionally sanctioned it is then a standard of care and must be considered when counseling patients and families.
- The power imbalance of the patient-physician relationship may inadvertently “nudge” consideration of
  - a less complicated shift toward a quick death compared to a more difficult, expensive, and care intensive path toward a slow death
  - financial incentives for “high value care” that will be inevitable where cost is considered equally with quality in the value of care given
  - As in social, family, professional expectations
- Deviation of policies, guidelines, and practices away from palliation in defining standards of care.
- Influence on family bonds, communication, trust in surrogate decision making
- Negative influence on the trust relationship

Physicians’ Boundaries and Obligations

- Respect Patient Autonomy—both positive and negative; there are limits
- Physician Autonomy—conscience and personal moral boundaries are balanced with professional obligations to care for the needy and vulnerable
- Eligibility requirements are challenging:
  - Prognosis, diagnosis, “seriously impaired”, and “terminal”
  - Defining the degree of suffering and quality of life
  - Those who cannot request or consent
  - Those who cannot take their own meds
  - Those who do or “might” change their minds
- For the patient, a right to assisted death may seriously compromise the natural right not to be killed.
Lessons Learned Moving Forward as a Profession

• The discussion must begin with a notion of shared understanding and universal commitment to access, beneficence, and compassion.
• Members of the HC team are bound in the sacredness of ministering to the suffering and dying... in pursuing this end selflessly we are all "ethical".
• Relief of all pain and suffering is not possible but care is never futile.
• Thoughtful professionals with moral integrity and divergent beliefs can live and work together in the service of patients.
• For professional organizations, a position of "studied neutrality" is contradictory and inconsistent with their mission; aside from serving a political end, neutrality diminishes the important task of advising and serving both members and their patients.
• A just health care system requires that stakeholders collectively remove barriers to optimal and safe care for all members of society, and in doing so, disadvantage none. This is never more critical than in EOL care.

End Notes on the Ethics of Legalizing AD

• Individuals make personal choices about suicide; our job is to respond without judgement to their needs.
• Universal commitment and compassion in response to our collective obligation to care for patients is understood—this is where the discussion should begin.
• Colleagues who assist death where legal are well meaning and tempered by conscience with a desire to help; the responsibility of others is to respond without judgement to their needs.
• As colleagues we must seriously contemplate how AD practices impact the integrity of the profession, relationships with patients, and the potential for harm that may come to those in and beyond our practice and society.
• Legitimizing AD by legalization and professional acceptance presumes a responsibility to study, enhance, monitor, regulate, bureaucratize, and standardize it as a practice. The risk is simply too great, resulting in...
  • the "standard of care" devolving as a means to "high value care" and cost control
  • being increasingly offered and utilized
  • vulnerable and disenfranchised populations being at risk
  • desensitizing physicians and society, thus distorting the notion of compassion and altruism
  • the erosion of confidence in physicians' role and retention
  • needed resources being diverted from meeting the growing need for more and better palliative care
  • laws that do not prevent abuse
  • interventions developed and marketed by industry, controlled by insurers, inequitably distributed

Life Liberty and the Defense of Dignity 2002

“We must care for the dying, not make them dead. By accepting mortality, yet knowing that we will not kill, doctors can focus on enhancing the lives of the those who are dying, with relief of pain and discomfort, moral and social support, and, when appropriate, the removal of technical interventions that are merely useless or degrading additions to the burdens of dying.”

Leon Kass, M.D., PhD
Chairman, President's Council on Bioethics 2001-05
Thank you!