

Whose Death Is It Anyway? Medical-Legal Conflict in End of Life Decision Making

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What Really Happens When the Rubber Meets the Road?

Why are end of life decision making choices so often disregarded?

Why Talk About End of Life Decision Making?

- Personal significance
 - Defining and promoting the values of autonomy, independence, and compassion
 - Considering the human cost of the American way of death
- Social significance
 - Defining and promoting the values of autonomy, independence and compassion for those unable to speak for themselves
 - Considering the financial cost of the American way of death

Why aren't these two lists exactly the same?

- Because we try very hard not to think about the allocation of scarce (health care dollar) resources when we think about end of life planning as individuals.
- Why is that?

So What is This About?



How Will Medicare Beneficiaries Experience 2010 Health Care Reform?

- In addition to “welcome to Medicare” physical, annual wellness visits will be reimbursed.
- What are these about?
 - “Advance Care Planning Consultation” (House Bill, Section 1233)
 - Medicare already provides for a hospice consultation for the terminally ill.
 - Federal law prohibits federally funded insurance for physician-assisted suicide.
 - But, the advance care planning consultation for healthy Medicare beneficiaries was removed from the 2010 Patient Protection and Affordable Care Act (Amended by the Health Care and Education Reconciliation Act of 2010).
- Was it the proximity of utility to autonomy that did it in?

Does this Medicare Beneficiary Know This?



Why Should We Care?

- Because, one day, we may all die
 - Who here expects to die?
- Because of the way we die, as Americans:
 - How will you die?
 - Sudden death?
 - Fatal diagnosis w. predictable decline?
 - Long slow decline?
- Because of the moral and legal authority of duly designated health care proxies to express and compel actions consistent with an incapacitated patient's express wishes or best interests.

Most Troubling Situations

- No advance directive and family conflict
- Imprudent selection of health care proxy
- No dispute resolution mechanism
- Failure to give voice to critical concerns

Most Common Causes of Death in the United States

- 15 Most Common Causes of Death in the United States (2007)

Cause	Percent of Total
• 1. Diseases of the heart	28.5
• 2. Malignant tumors	22.8
• 3. Cerebrovascular diseases	6.7
• 4. Chronic lower respiratory diseases	5.1
• 5. Accidents (unintentional injuries)	4.4
• 6. Diabetes mellitus	3.0
• 7. Influenza and pneumonia	2.7
• 8. Alzheimer's disease	2.4
• 9. Nephritis, nephrotic syndrome, and nephrosis	1.7
• 10. Septicemia (blood poisoning)	1.4
• 11. Suicide	1.3
• 12. Chronic liver disease and cirrhosis	1.1
• 13. Primary hypertension & hypertensive renal disease	0.8
• 14. Parkinson's disease (tied)	0.7
• 15. Homicide (tied)	0.7

Source: CDC/NHS, National Vital Statistics System

Where Do We Die?

- 50% of Americans die in a hospital
 - 1 in 5 Americans die in ICU (Critical Care Medicine, 2004)
- 25% die in nursing homes (Journal of Palliative Medicine, 2004)
- An estimated 20% die at home (Critical Care Medicine, 2006)
- 90% want to die at home (1999 Harvard Public Opinion Poll)

Who Might We Meet as We Die?

- If we fail suddenly, we might meet an EMT.
- That EMT operates under a system wide resuscitation policy, that typically allowed EMT's to forego resuscitation only if:
 - Presented with a written DNR
 - Obvious signs of irreversible death

California's Emergency Medical Services Prehospital Do Not Resuscitate Form

- Specific resuscitative measures may be foregone:
 - Chest compressions (CPR)
 - Assisted ventilation
 - Endotracheal intubation
 - Defibrillation
 - Cardiotonic drugs
- What California's DNR form does not cover:
 - Other emergency medical care
 - Comfort measures
 - Difficulty breathing
 - Major bleeding

What's an EMT to Do?

- 2007 Los Angeles County EMS System new resuscitation protocol:
 - Permits paramedics to forego attempted resuscitation in two additional circumstances
 - Family member on scene, verbally requests DNR in accordance with patient wishes, but without DNR document
 - or
 - Patient found in asystole (“flatline”) and 10 minutes have passed between collapse and CPR

Who Else Might You Meet as You Die?

- You might meet a physician in a hospital.
 - A physician you know
 - A physician you don't know
 - More than 20,000 hospitalists practice today in the United States (NEJM, 2007)

Whose Death is it Anyway?

- Where did this title come from?
 - From an October, 2009 NYT article by a nurse, based on an actual case in an acute care hospital.
- “Back and forth they went, until finally the doctor accepted that he was not going to change the patient’s mind and that he couldn’t bully the patient into accepting treatment.”
- “But the doctor did refuse to refer the patient to hospice. The medical team listed the patient as leaving A.M.A. — against medical advice — and said a hospice referral posed too great a liability risk in that case.”

What Tools Do We Have to Manage Such a Disconnect?

- Legal system crafted tools
- Medical system crafted tools

The Problem with Oral Directives

- In the face of the lack of an advance written directive, courts have imposed a clear and convincing evidence standard of proof regarding right to die/right to decide cases.
- *Cruzan v. Missouri Dep't. of Health* (US 1990) (US Supreme Court affirms Missouri's right to impose this standard)

Missouri's State Interest in *Cruzan*

- Preserve life
- Prevent suicide
- Protect innocent third parties
- Uphold the ethical integrity of the medical profession

Conservatorship of *Wendland* (CA 2001)

- Robert Wendland fought with his wife and brother over his self destructive drinking and driving days before the accident that rendered him incapacitated.
- Robert Wendland told his wife, in direct response to her concern about his eventual incapacity:
 - “If that ever happened to me [severe and permanent disability] you know what my feelings are. Just let me go.”

CA Probate Section 4670-4698

- Requirements of a written advance health care directive
 - Date of execution
 - Signature
 - Notary or two witnesses
 - Witnesses must be adult
 - Witness to signing or acknowledgement
 - Restrictions on witnesses
 - **Patient's health care provider may not be a witness**

CA Probate Codes Section 4675

- Special rules for residents of SNFs
 - Special witness requirements
 - “It is the intent of this subdivision to recognize that some patients in skilled nursing facilities are insulated from a voluntary decision making role, by virtue of the custodial nature of their care, so as to require special assurance that they are capable of willfully and voluntarily executing an advance directive.”

Advantages of the Legally-Designed Model

- Elevates autonomy and dignity above all
- Avoids problems w. doctor-patient conflict
 - Because the doctor is informed after the fact
- Enables patients to act independently or seek hired assistance

Disadvantages of the Legally-Designed Model

- Is it self enforcing?
- If not, who is going to enforce it?
- What weight can it carry against the punitive doctor who refuses the hospice referral under the cloak of medical liability?
- What weight can it carry in the face of hospital institutional procedures that bar visitor access to an incapacitated patient unrelated by blood or marriage?

Respecting the Rights Patients to Receive Visitors and to Designate Surrogate Decision Makers

- Why does it take the direction of the President of the United States to require HHS to initiate rule-making on visitation rights and surrogate designation rights?
 - Under the Federal Administrative Procedure Act, the President may direct a federal administrative agency to initiate rule-making by memorandum.
 - But why does it take this?

The Story of Lisa Pond's Death

- The U.S. District Court for the Southern District of Florida dismissed Lambda Legal's lawsuit on behalf of Janice Langbehn, Lisa Pond's partner of 17 years who was kept from her bedside during her final hours of life in the Jackson Memorial Hospital in 2007. Agreeing with the Public Health Trust of Miami Dade County's motion to dismiss, the court ruled that "the hospital has neither an obligation to allow their patients' visitors nor any obligation whatsoever to provide their patients' families, healthcare surrogates, or visitors with access to patients in their trauma unit."



Langbehn v. Public Health Trust of Miami-
Date County
(S.D. of Florida, 2009)

- “As far as I can tell, no court has held (or even suggested) that a doctor at a trauma center, or a social worker at such a facility, has a fiduciary relationship with a patient’s relatives (even those who are health care surrogates) so as to require the doctor or social worker to allow the relatives visitation with the patient, or provide crisis and bereavement counseling, or keep the relatives apprised of the patient’s status.”

Langbehn-Pond

- A complaint filed on behalf of Lisa Marie Pond's estate and her life partner, Janice Langbehn sounding in tort and related claims was dismissed on September 29, 2009.
- http://data.lambdalegal.org/in-court/downloads/langbehn_fl_20090929_order-granting-motion-to-dismiss.pdf

POLST

- Physicians Orders for Life Sustaining Treatment (effective 1/1/09 in CA)
 - What makes it a physician's order?
 - NY calls it “Medical Orders”
 - Why target to individuals in last year of life?
 - Why target to SNF and AL residents?
- Why develop a POLST version targeted to individuals with intellectual disability?
- <http://www.ohsu.edu/polst/>

Advantages of the HC Provider-Centered Model

- Your GP or internist will have to be on board, or it will not be signed.
- Doctors' orders minimize hospitalist/intensivist override.
- Contemplates a built in counseling and completion aid in your personal physician.

POLST Disadvantages

- How many of you have a personal physician?
- Will physicians or physician extenders provide the counseling component?
- Who will enforce it?

When the Rubber Meets the Road

- *Welcome to the Departure Lounge: Adventures in Mothering Mother*
Meg Frederico (2009)

“As a result of this little drama, I plan to get DNR tattooed on my chest in big blue letters, just below the clavicle, where you can’t miss it, along with my lawyer’s name and phone number. Because, frankly, nothing stands between you and a return trip from the grave but the right paperwork, and if you can’t find it when you need it, you are totally out of luck.”