Getting to "No" You:

Ethical Issues in End of Life Care

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"Is It Wrong to Provide Futile CPR?" Truog, NEJM Feb 11, 2010

- 2 yo, frontal encephalocoele.
- No meaningful neurologic function.
- Parents refused palliative care, DNR.
- Multiple ICU admissions.
- Cardiac arrest, CPR, multiple attempts at central & intra-osseous lines.
- "Futile and brutal"
- Parents said "thank you."

Truog: Justifications

- Not all families share the vision of a good death as peaceful and comfortable
- “Giving up” unacceptable in this family’s culture
- Family might feel regret later.
- Treated the family with respect, care and compassion
- Patient’s interests had waned, no suffering; family’s psychological interests took priority

Concerns/Criticisms

- Where does this duty end?
  - Brain dead patient?
  - Recurrent CPR?
  - Accept for multiple admissions?
  - Dialysis, transplantation, home ventilator?
  - Other symbolic tests, treatments?
    - Serial MRI’s, PET scans

Associated Press

Hospital Seeks to Pull Plug on Brain-Dead Boy, 12

Thursday, November 06, 2008

The hospital is seeking a court order that affirms its plan to disconnect the boy from a ventilator and to discontinue intravenous medications that keep his heart beating.

Concerns/Criticisms

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Concerns/Questions

- Emotional toll on nurses, other physicians
- Using child's body and intensive care as a means of psychotherapy
- Dishonest to parents: pretending that resuscitation might succeed

Two more familiar issues

- Futile treatment won't go away
  - False legal fears (Risk may be zero)
  - Real political fears (Schiavo)
  - Perceived duty to family > patient
- *Discussing* rationing is still taboo
  - Clinton → Obama
  - Press
  - Key opinion leaders need to lift the taboo

Futility debate

- Consensus
  - Medical futility: Rx will not achieve the medical goal for which it is designed.
    - E.g., Ventilator in pulmonary agenesis
    - Acknowledged to be rare
  - Social futility: Rx works, but the quality of life does not justify the costs
    - Not a medical judgment
    - Must be negotiated with family, staff, to a point

Extreme social futility

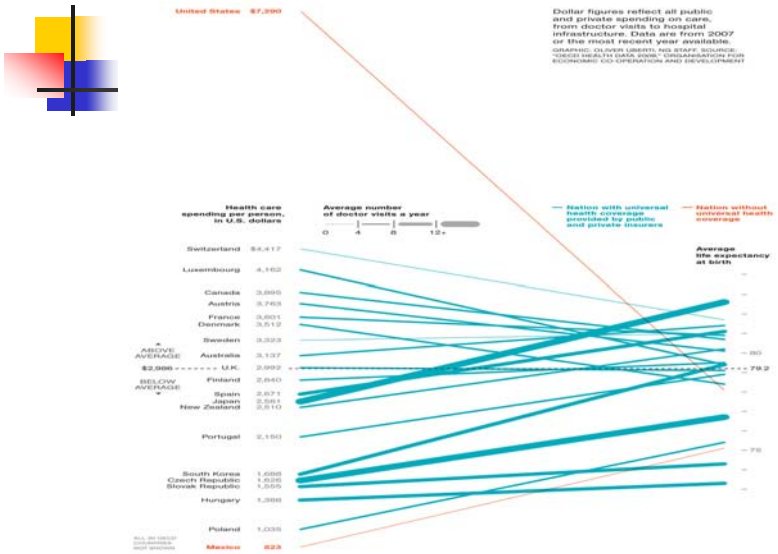
- Patients with no plausible prospects for leaving the hospital alive or experiencing human interaction.
- Insistent families
  - Misunderstanding about prognosis
  - Religious views re sanctity of life
- Institutional fear of political consequences of over-riding family wishes
  - Dominance of risk management considerations over patient's interests
  - Fear of going to jail > fear of going to hell

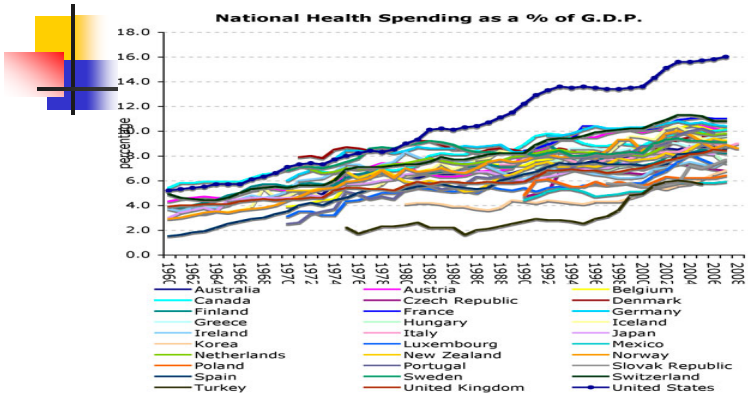
Legal vs political risks

- Difficult to find a single case of liability for withholding/withdrawing LSMT over family objection
  - MGH, CNMC prevailed
- Even active euthanasia is difficult to prosecute
  - Kevorkian: 100+ cases, 4 trials

Relevance of cost

- Futility discussions become most contentious when linked with high-technology support
  - Burden on staff (“Abuse”)
  - Pressure on ICU beds
  - Questions about cost/QALY


United States $7,290
Dollar figures reflect all public and private spending on care, from doctor visits to hospital infrastructure. Data are from 2007 or the most recent year available.
Health care spending per person, in U.S. dollars
Average number of doctor visits a year
0
4
8
12+
Nation with universal health coverage provided by public and private insurers
Nation without universal health coverage
Average life expectancy at birth
Switzerland $4,417
Luxembourg 4,162
Canada 3,895
Austria 3,763
France 3,601
Denmark 3,512
Sweden 3,323
ABOVE AVERAGE
Australia 3,137
$2,986
U.K. 2,992
BELOW AVERAGE
Finland 2,840
Spain 2,671
Japan 2,581
New Zealand 2,510
Portugal 2,150
South Korea 1,588
Czech Republic 1,526
Slovak Republic 1,505
Hungary 1,388
Poland 1,035
Mexico 823
80
79.2
75


National Health Spending as a % of G.D.P.
percentage
18.0
16.0
14.0
12.0
10.0
8.0
6.0
4.0
2.0
0.0
1960
1962
1964
1966
1968
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Australia
Austria
Belgium
Canada
Czech Republic
Denmark
Finland
France
Germany
Greece
Hungary
Iceland
Ireland
Italy
Japan
Korea
Luxembourg
Mexico
Netherlands
New Zealand
Norway
Poland
Portugal
Slovak Republic
Spain
Sweden
Switzerland
Turkey
United Kingdom
United States

Perspective

- End of life costs not biggest contributor to runaway inflation, but not trivial
  - 27% Medicare $300B budget for last year of life
  - Dirksen: “A billion here, a billion there....”
- Enormous variance
  - UCLA $50K vs Mayo $25K last 6 months
    - “If you come into this hospital we are not going to let you die.” Dr Peter Feinberg, CEO
  - Could save $700B if all were like Mayo
  - “We have no idea what we’re getting for the extra $25,000” Peter Orszag

Causes of inflation

- Administrative waste
  - $300-400B savings if single payer
- Medical waste
  - $300-$500B ineffective dx/rx
    - E.g., Mammography age 70-79
- Aging population
- New expensive technology
- Eliminating waste is a one-time saving, only postponing the need to ration

Eliminating waste is a one-time saving

Cable TV, 10 channels, $1/each

Double each year

	1	2	3	4	5	6
$1	$10	$20	$40	$80	$160	$320
$.50	$5	$10	$20	$40	$80	$160

Rationing as taboo

- Clinton Health Care Task Force
  - Directive not to use the word
  - Consumer panel
- Obama health care reform
  - Denied rationing would be necessary
  - Mammography: Assured it would always be funded at all ages

Mammography 70-79 yo

- If woman is at *high risk* for breast cancer, life expectancy will be increased by an average of 8 hours
  - Cost per QALY: $1.2 million
- If woman is at *normal risk* for breast cancer, life expectancy will be decreased by 5 hours
- 40-49 yo: Increase in average life expectancy measured in days

Futile CPR

- If we owe intensive care to all patients who want it, even when futile, we will never get to the discussion about denying effective care
- Rationing means denying effective care
- Leadership is needed to bring it out of the closet, into the mainstream discussions
  - Not whether to ration, but how

Conclusions

- Health care is a/the major cause of personal, business and governmental bankruptcy in the US and getting worse.
- There is no entitlement to all effective care, and certainly not futile care.
- People/institutions in leadership positions need to attack the taboo on discussions of explicit rationing.
- Need to get to “No” the people better.

“You can always trust the American people to do the right thing, after they have exhausted all of the other possibilities.”

Winston Churchill

Separator slide

- Following slides for possible use during discussion

Medical futility

- Can never say prospect for meaningful survival is zero
  - Misdiagnosis
  - Self-fulfilling prophecies
    - 1000 gm infant in 1964: “Not viable”
    - Anencephalic infants surviving 2, 14 years
  - 1/million is not zero
    - If $1,000 per pt → $1 Billion per life saved
    - Whether worth it is a value judgment

UCLA vs Mayo

- “If you come into this hospital, we’re not going to let you die.”

  Dr. David T. Feinberg

  CEO, UCLA Medical Center