Perspectives:“End of Life” Care

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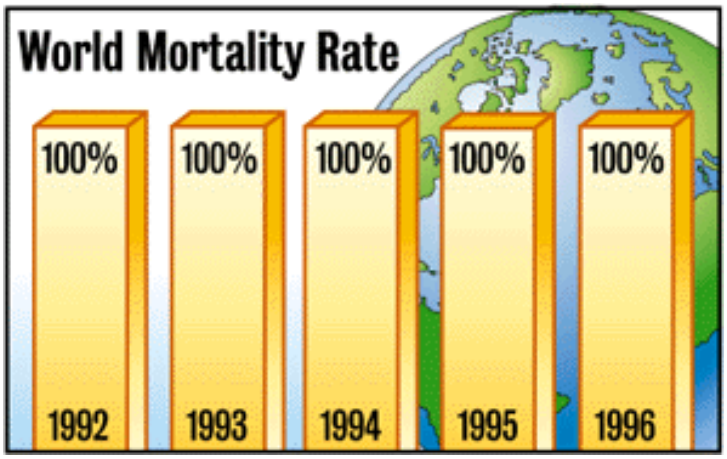
Framing Our Issues

- Travelling the Valley of the Shadow of Death…
- Trajectories and categories
- Numbers and caregivers
- Lies, manipulations, and statistics

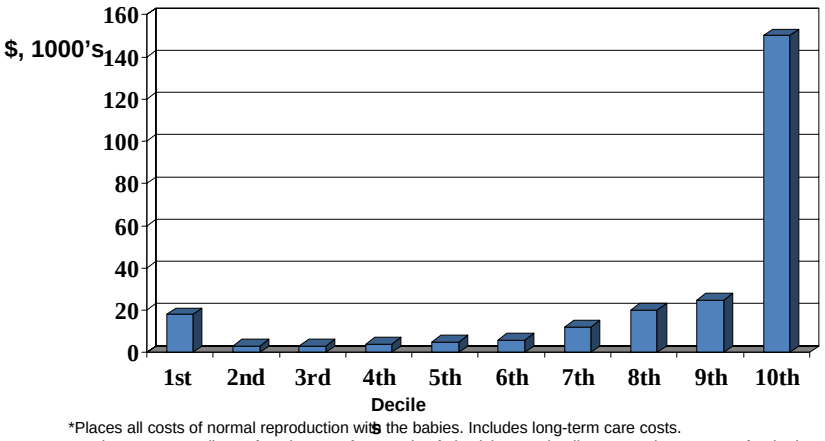
And what we could do…



How Americans Die: A Century of Change

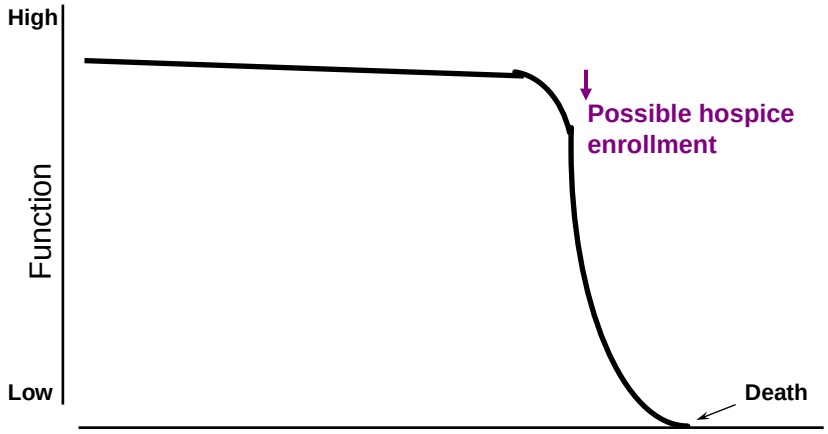
	1900	2000
Age at death	46 years	78 years
Top Causes	Infection Accident Childbirth	Cancer Organ system failure Stroke/Dementia
Disability	Not much	2-4 yrs before death
Financing	Private, modest	Public, substantial- in US - 83%, Medicare ~½ of women,Medicaid

Rough Estimate of Costs per Decile over the lifespan*



*Places all costs of normal reproduction with the babies. Includes long-term care costs.
• Estimates are medians of estimates of a sample of physicians and policy researchers, except for the last decile
•The last decile's estimate are derived from Lubitz et al1995 and from MedPAC report 2000.

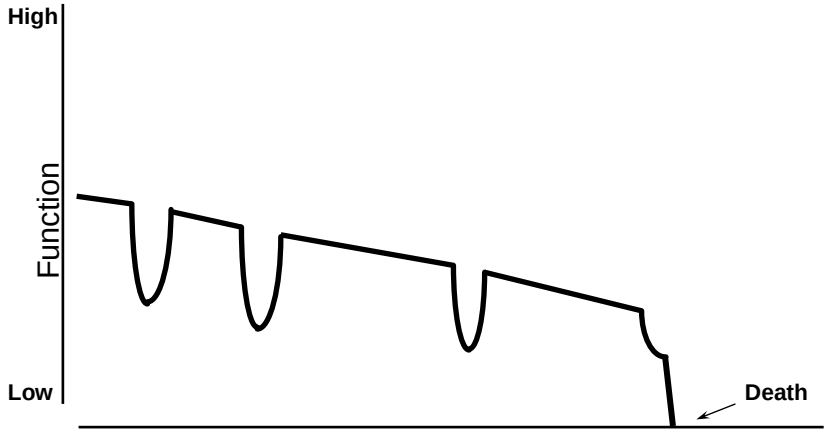
“Cancer” Trajectory, Diagnosis to Death



Onset of incurable illness → Time

-- Often a few years from onset, But decline usually < 2 months

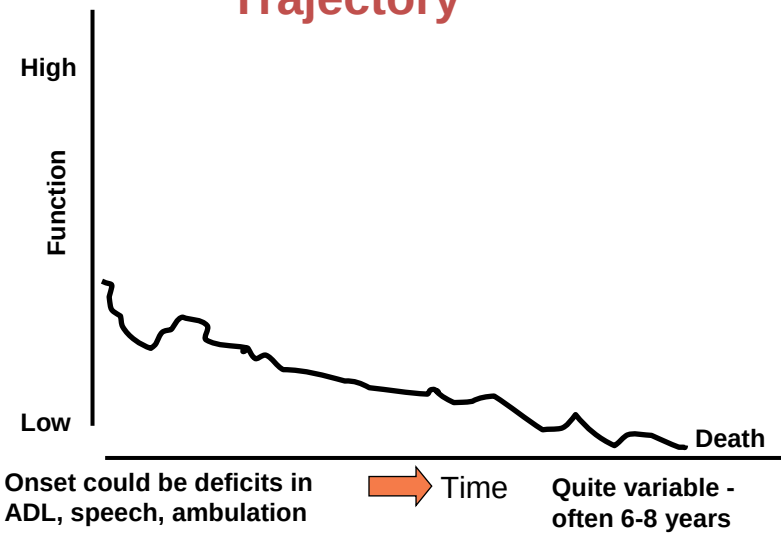
“Organ System Failure” Trajectory



Begin to use hospital often, self-care becomes difficult → Time

~ 2-5 years, but death seems “sudden”

"Frailty/Dementia" Trajectory



Managing a Hotel Chain….

- Would you build just one kind of hotel?
- Would you wait to design the hotel until a sleepy person showed up looking for a room?
- *No* – you would design hotels around the priorities of the most common populations, then customize for individuals as needed
- Mass customization and market segmentation!
- **We can use these strategies for health**

The Bridges to Health Model

POPULATION	PRIORITIES
1. Healthy	Stay well
2. Maternal, infant	Safe start
3. Acutely ill	Get well
4. Chronic condition	Slow progression
5. Stable, disabled	Life opportunities
6. EOL, short "dying"	Comfort, Control
7. EOL, erratic	Few episodes, plan
8. EOL, long decline	Personal care, family

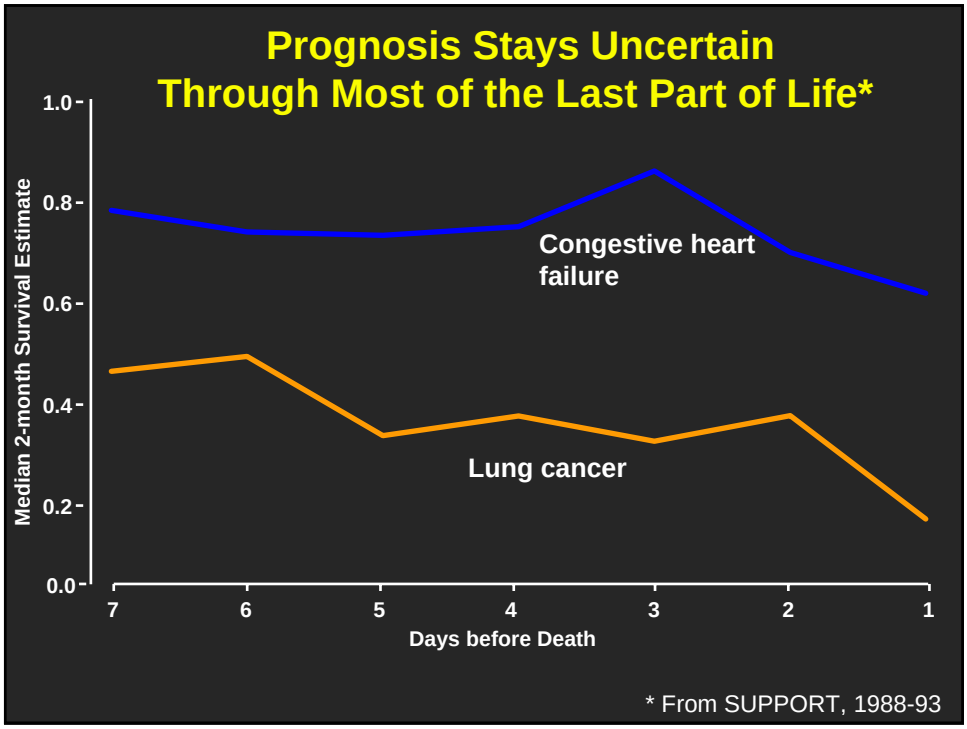
Milbank Quarterly, June 2007

Who is in the Category "End of Life?"

NOT "reliably short prognosis" (e.g., < 6 months) *because*

- most people are stable
- with serious illness
- within a week or two of their deaths –

For example – the average person dying of heart failure has 50-50 chance to live 6 months, 2 days before death



Who Should we Categorize as "End of Life?"

Better answer -

- ✓Seriously ill and disabled
- ✓With condition(s) that will not substantially improve,
- ✓Will worsen,
- ✓And will cause death.

(No particular survival time is part of the definition)

The *"No Surprise"* Population

Would it be a surprise for this person to die within six months? (or a year – doesn't matter)

If "no surprise" – then "end of life" care

- Priorities: planning ahead, comfort, family
- Optimal medical care
- Can continue for a few years
- Includes the short time when dying soon

Gold Standards Framework, Britain
www.goldstandardsframework.nhs.uk

Caregivers

1990
11 to 1

2010
10 to 1

2030
6 to 1

2050
4 to 1

www.dyingwell.org

How the US supports caregivers…

- No assessment of capability or willingness
- Little engagement or respect
- No regular income support
- No dependable respite care or back-up for absences
- Unreliable training and support
- Frequent ruin of caregiver retirement security
- Almost no research

YET – almost all of us will be caregivers

What is working

- Wider availability of hospice, palliative care, geriatrics – symptom care and planning
- Geographically-anchored reforms, system CQI
- ID and learn from “positive deviants”
- Normalizing honesty and planning
- Transition reduction and coaching or bridging
- Feedback from patients, families, downstream providers

What else could work

1. Tell patient/family stories. Create awareness and preferences.
2. Organize political power when high-cost treatments and caregiver shortages create opportunities.
3. Enable regional improvement work.
4. Build capacity for optimal care - honoring choices is a hollow victory if you have no good options!
5. Label ordinary dysfunctions as serious errors:
   a. Avoidable hospitalizations,
   b. Not planning ahead,
   c. Manipulating patients/families with incomplete information,
   d. Inept transitions,
   e. Poor symptom control

For example, The Goldilocks Paradigm

- Some people are too well for hospitals
  (they are put at risk for little gain)
- Some people are too sick for hospitals
  (they are put at risk for little gain)
- Some people are *just right….*

The trick is to hospitalize *only* the Just Right!

How?...

Keep the "Too Sick" out of hospitals

- Good support in the community
  - Quick
  - Reliable
  - Can handle most symptoms and situations
  - Including respiratory distress
  - Cope with poor housing, caregiver limits
- Advance planning
  - Especially during earlier hospitalizations
  - Plan must be available
  - Full plan of care – not just CPR

An especially sensitive issue….

How can anyone know that the patient's dying was actually timely?

(appropriate diagnosis and treatment – and not death from inattention, denial of treatment, or deliberate cause)

Possible Answers

- Standards about diagnosis and severity
- Standards about choice and planning
- Autopsies
- Reporting concerns, threats to safety

Why Bother?

- Suffering (unnecessarily severe)
- Costs (unnecessarily high)
- Track record of successful improvements
- Unpopularity of status quo

So – we might have the political will to reduce suffering, improve care and reduce costs

Why Bother?

It was my father this time,

but next time it will be your father, and then you, and then your child.

I have heard it said by cynics that the quality of medical care would be far better and the hazards far less if physicians, like pilots, were passengers in their own airplanes.

We are.

Berwick, Quality comes home. Ann Int Med 1996; 125:839-832