

That Last Phase of Life – Illness, Disability, Caregiving and Death

**Opportunities for Innovation in Clinical
Research: From Molecule to Medicare - Part II**

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Research Directions

1. Demographics
2. Public perceptions, categories
3. Quality of care
4. Value of care, preferences of patients
5. Small area variation
6. Determinants of care pattern
7. Basic science – pain, depression, etc.



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How Americans Die: A Century of Change

1900

2000

Age at death

46 years

78 years

Top Causes

Infection

Cancer

Accident

Organ system failure

Childbirth

Stroke/Dementia

Disability

Not much

2-4 yrs ave. before death

Financing

Private,
modest

Public, substantial-
in US - 83% in Medicare
~1/2 of women die in
Medicaid

Why target fatal chronic illness?

- It's **big** – About 1/3 of lifetime expenses, and most of the lifetime's suffering with ill health
- It's **bad** – care is unreliable, often harmful
- It's **ugly** – little political will for reform – especially for frailty, dementia, family caregivers, housing, and costs

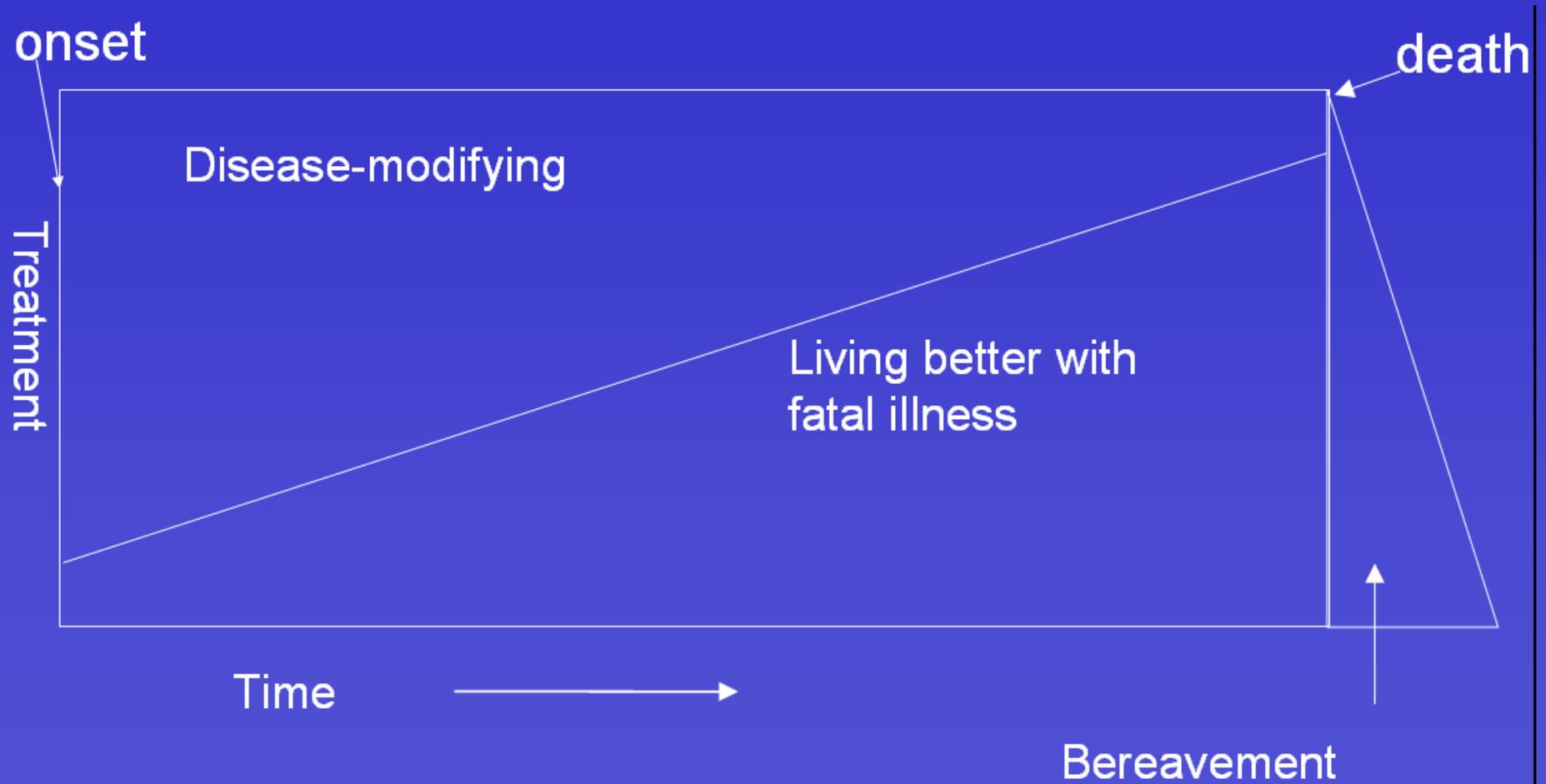
Who is “dying” – Our Old Concept



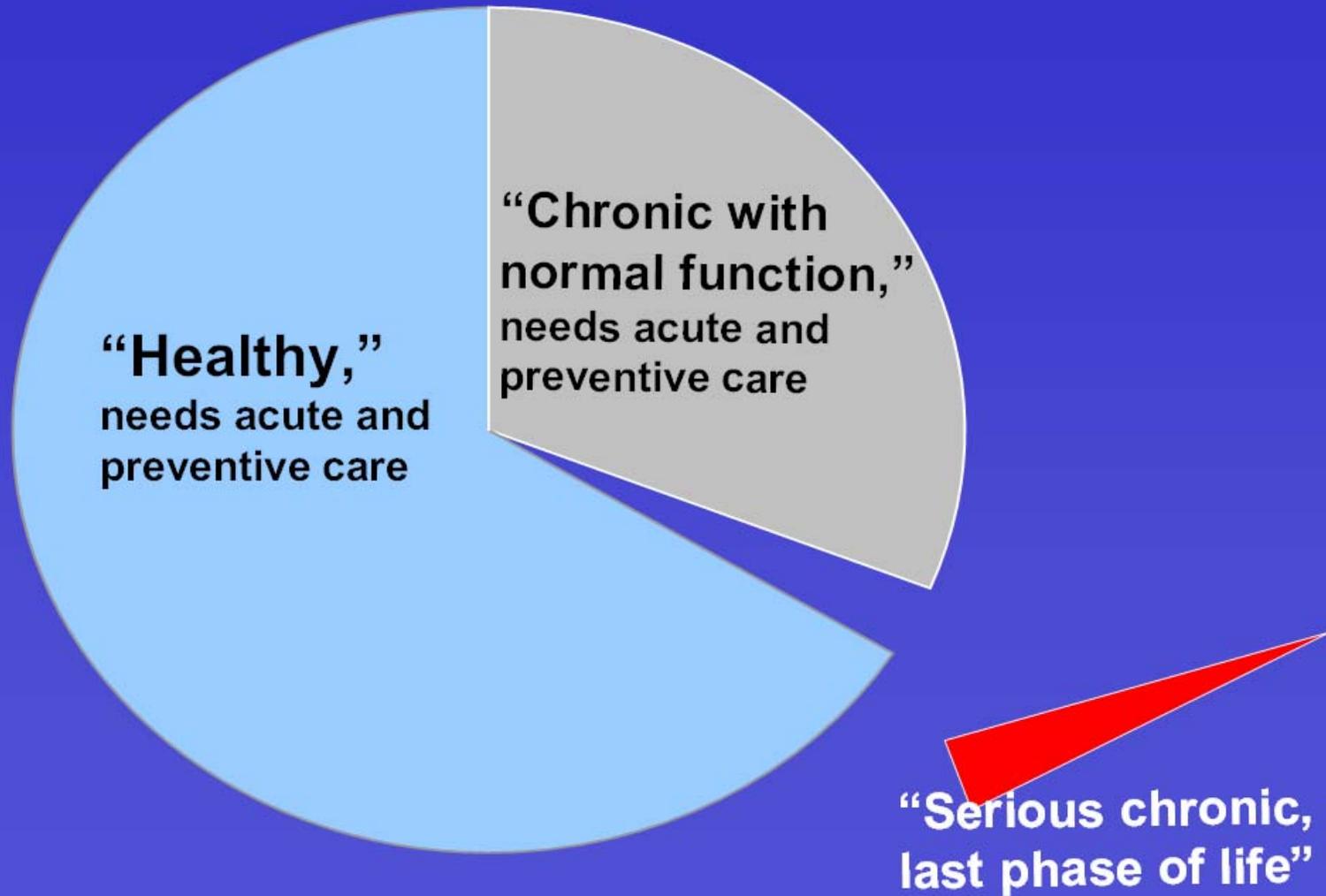
Severity of Illness, not Prognosis

- Prognosis for individuals often stays uncertain, even close to death
 - Median patient with chronic heart failure had 50-50 chance to live 6 months *on the day before dying*
(*Research finding that changed policy*)
- Severity of illness dictates needs
- Most patients need *both* disease-modifying treatments *and* help to live well with disease

A Better Model for the “last phase of life”



Divisions by Health Status in the Population



Framing the Research Question

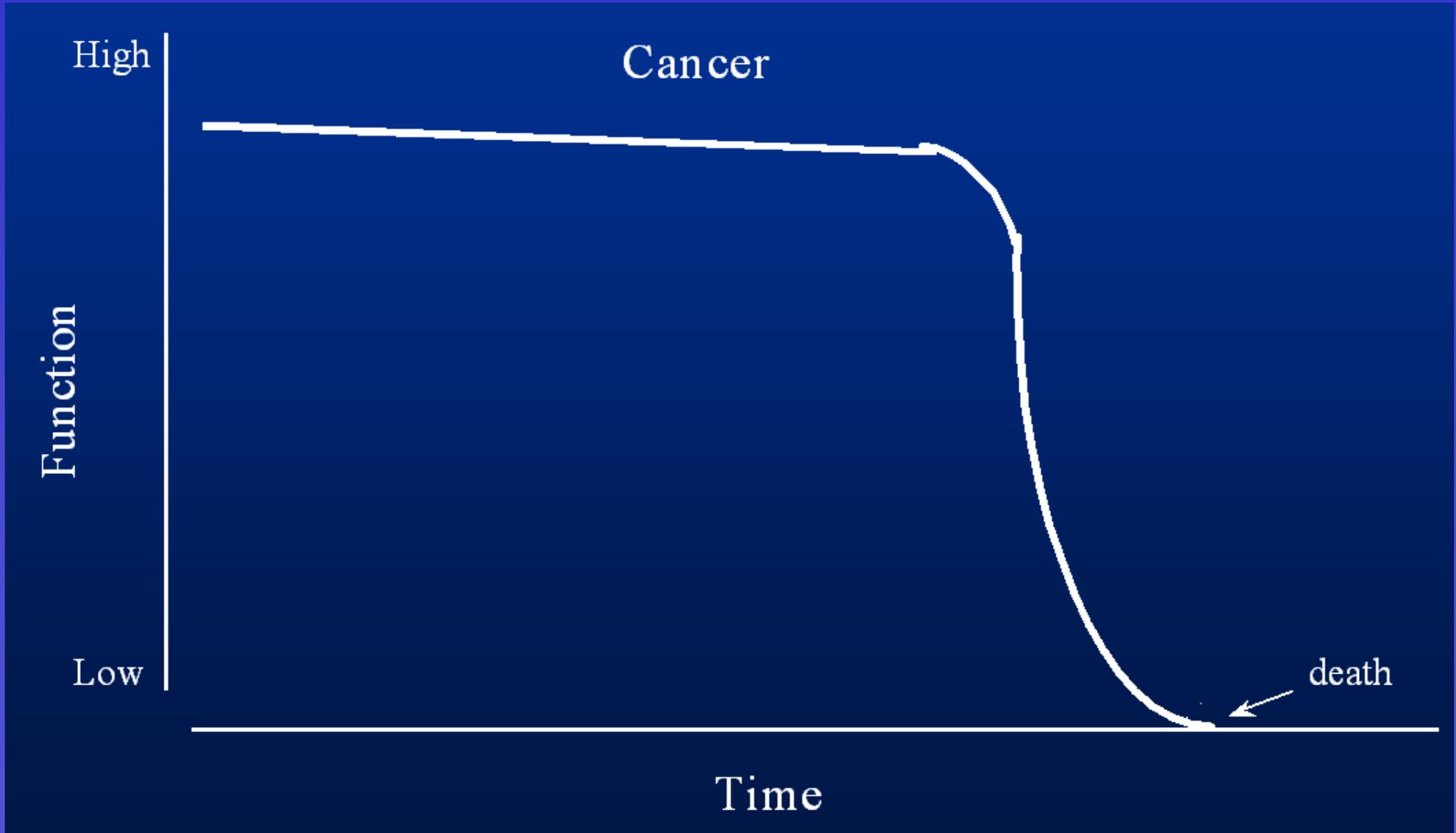
How would one “study” better categories and models?

1. Test it out in real world applications
2. Test specific aspects for such elements as validity, calibration, sensitivity
3. Test whether application of the model correlates with acceleration of improvement

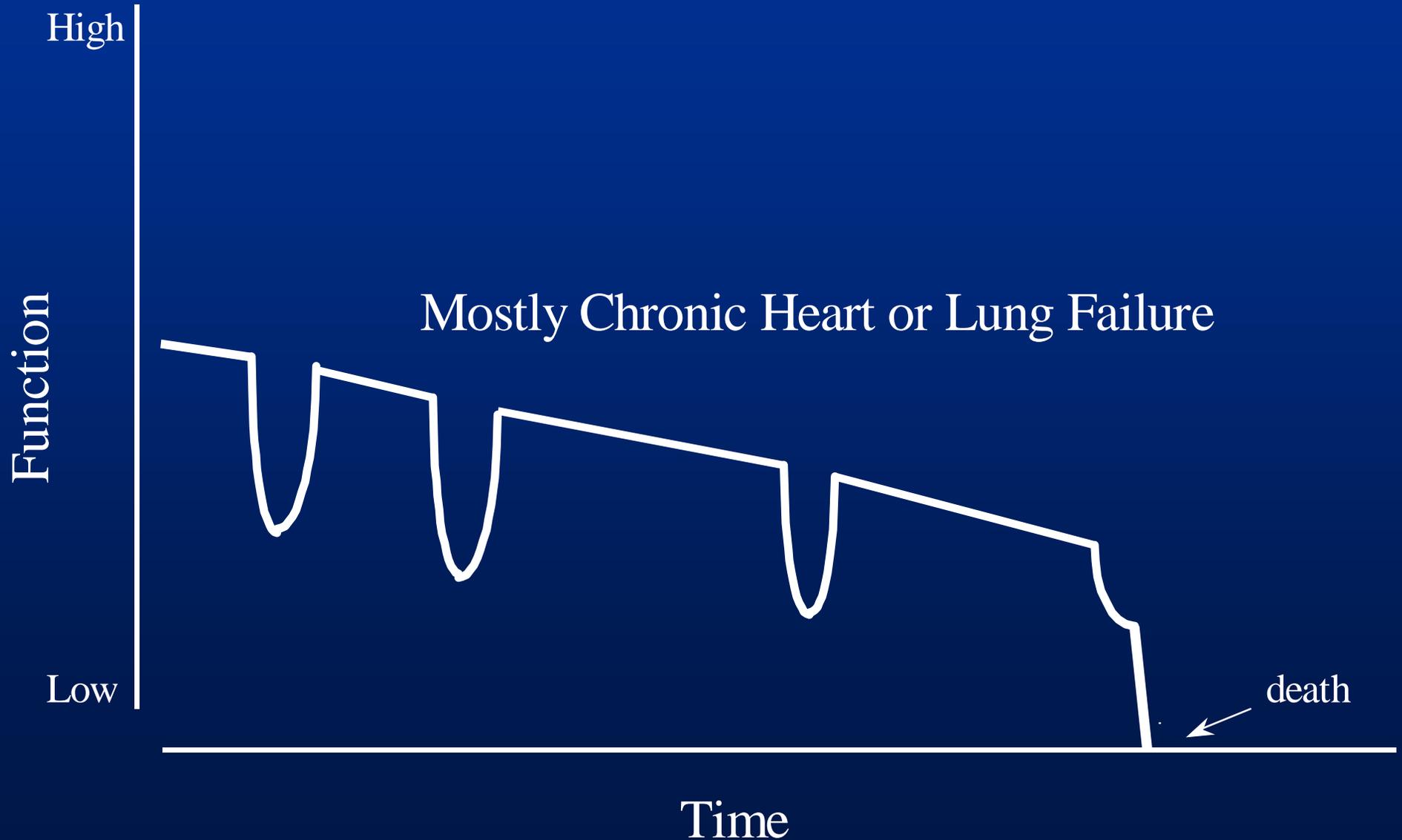
Target population for improving the “Last Phase of Life”

1. Sick (disabled, dependent, debilitated)
2. Generally getting worse and will die from current illness(es)
3. Will die without a period of being well again

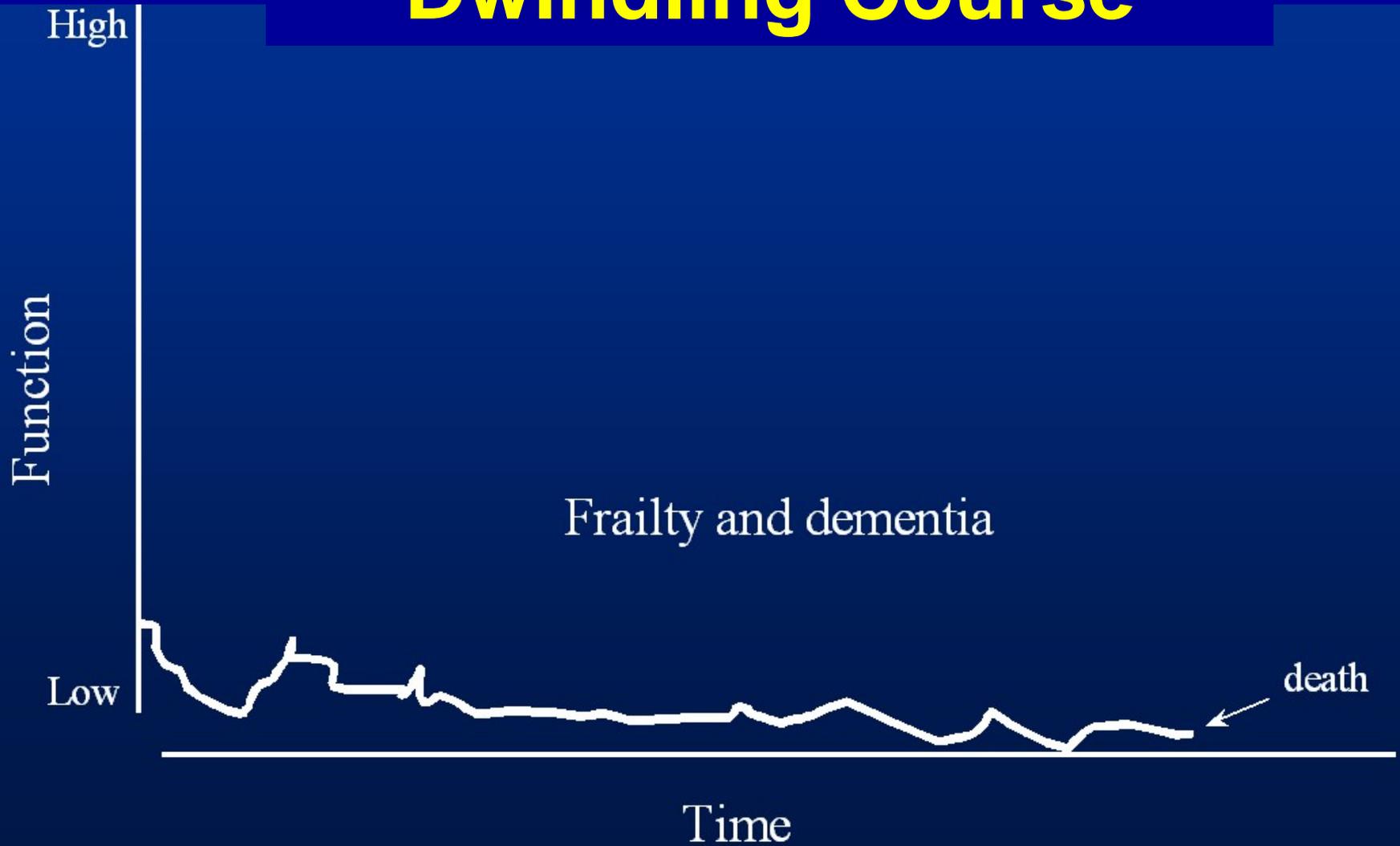
Short Decline, "Dying"



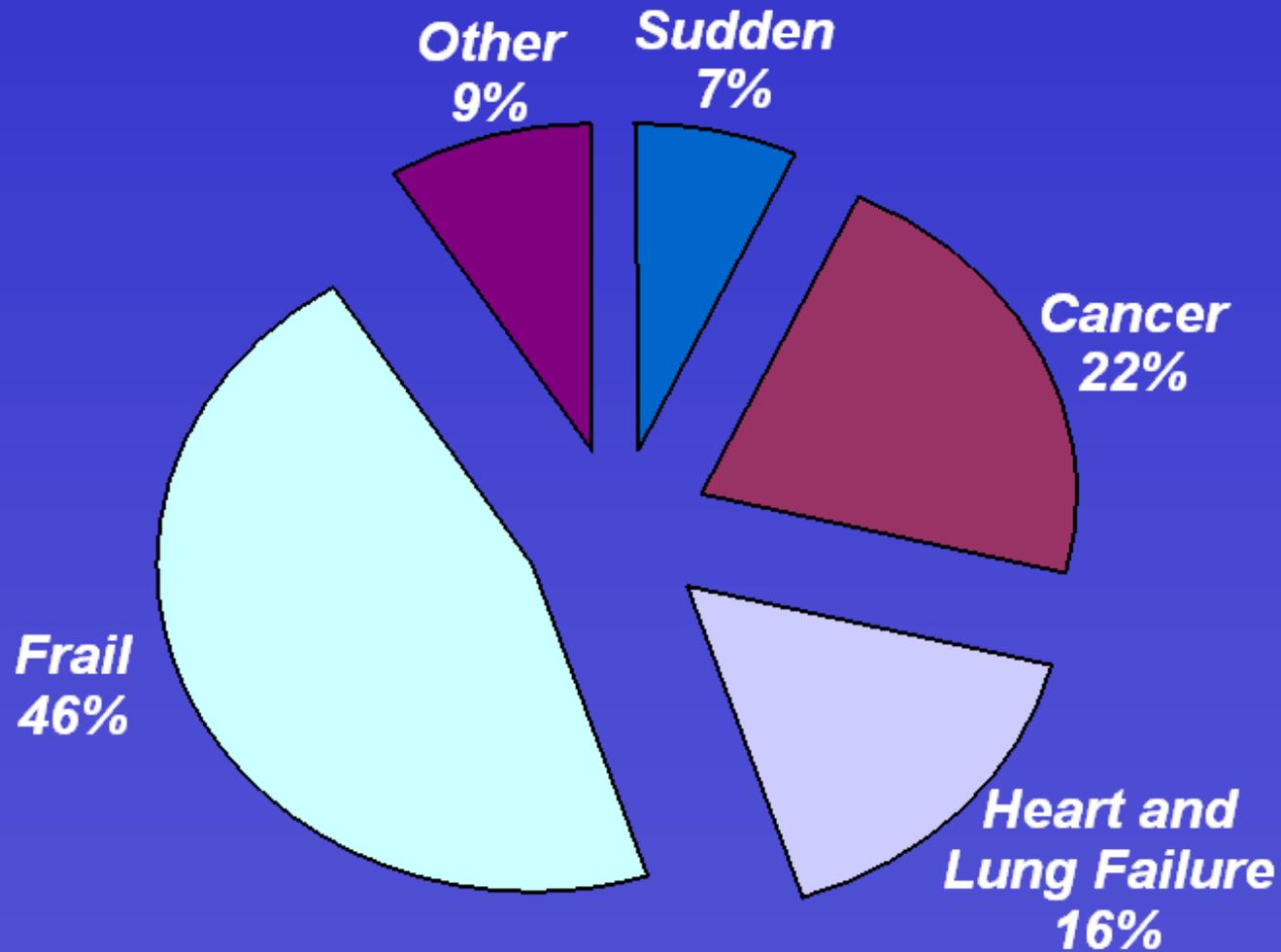
Exacerbations and Sudden Dying



Dwindling Course



U.S. Medicare Decedents



How would one study this?

Classify a population – see which patients have controversial classification or none

Trace the rates in existing data – claims, Medicare Current Beneficiary Survey, VA electronic records

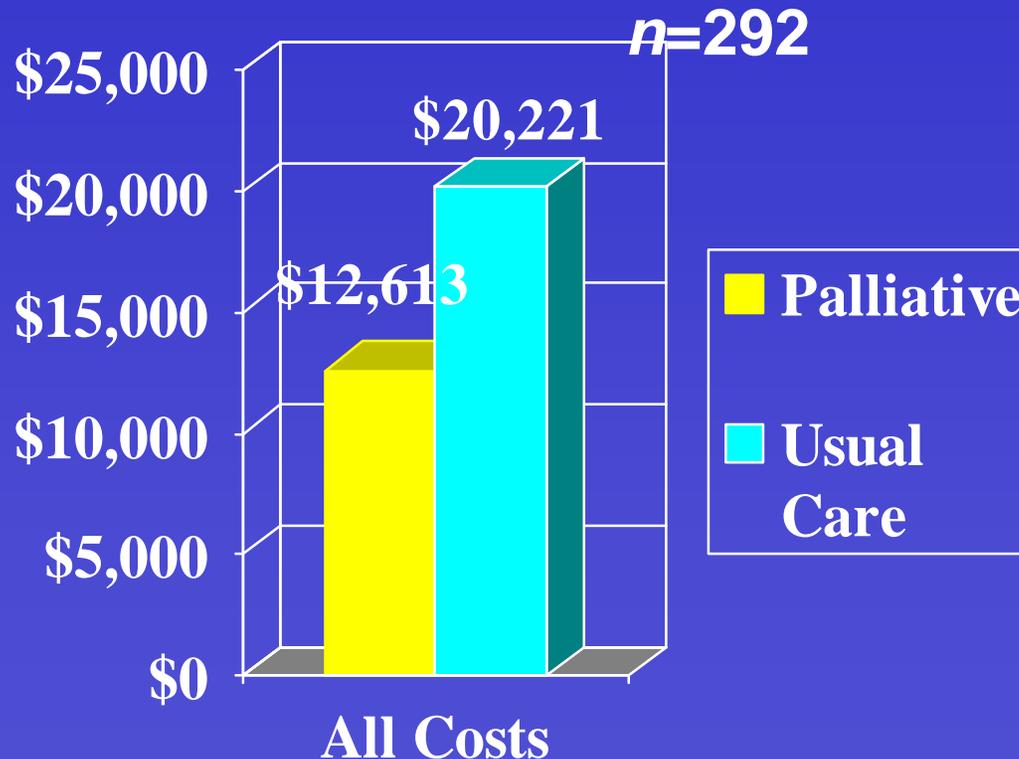
Test the match of the populations with services in implementation trials

Populations to Serve	Priority Concerns
1. Healthy	Stay well
2. Chronic condition	Prevent or delay progression
3. Maternal and infant	Safe start
4. Stable, disabled	Life opportunities
5. Acutely ill	Get well
6. EOL, short decline near death (mostly cancer)	Comfort, Dignity, Control, Life closure
7. EOL, intermittent exacerbations with sudden dying (mostly heart/lung failure)	Self-care, Avoid episodes, Longevity, Contingency planning
8. EOL, long dwindling course (mostly frailty and dementia)	Career support, Housing, Dignity, Skin care, Mobility, Planning

Why would anyone focus on this?

- Focuses research and policy on important issues
- Frames a reform in usable terms
- Motivates advocates

Total Service Costs



$p < .001$ $F = 16.66$

- Program enrollment, adjusting for age, disease, severity of illness, and days on service, explained 16% of the variance in total service costs
- Adjusted costs of care for those in PC were 37.6% less than those receiving UC

The Pool of Family Caregivers

1990

11 to 1



2010

10 to 1



2030

6 to 1



2050

4 to 1



About family caregivers

- Provide most of the care for the sick and disabled
- Face poverty, lack health insurance, have no vacation
- Do not identify as a group with shared political interests
- Old age and palliative care providers have not been strong allies for family caregivers

The state of research

- Only slightly better than worthless
- Can't even count caregivers reliably
- Myriad studies of how to reduce burden of a few dozen dementia patients' family members – obvious things, mostly
- Few high-quality studies of population dynamics, economics
- Few generalizable studies of interventions

Research on caregiving?

Demography

Retirement income and security

**Labor conditions – benefits, injuries,
training**

Burdens and benefits

Effects of potential interventions

**Public information and motivation for
politics**



Orbis Terrarum, 1675 by Visscher

Resources for Reform

Patients and families

- Web – www.growthhouse.org
- Book – Handbook for Mortals (Oxford U Press)

Policy

- Sick to Death and Not Going to Take it Anymore!
Reforming Health Care for the Last Years of Life
(U California Press, 2004)

Quality Improvement

- Improving Care for the End of Life
(Oxford U Press., 2001)