Care to Count on When You Need it Most-- Reforming Health Care Policy for Fatal Chronic Illness

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Americans for Better Care of the Dying

www.medicaring.org; www.abcd-caring.org

Federal Trade Commission, May 30, 2003

How Americans Die: A Century of Change

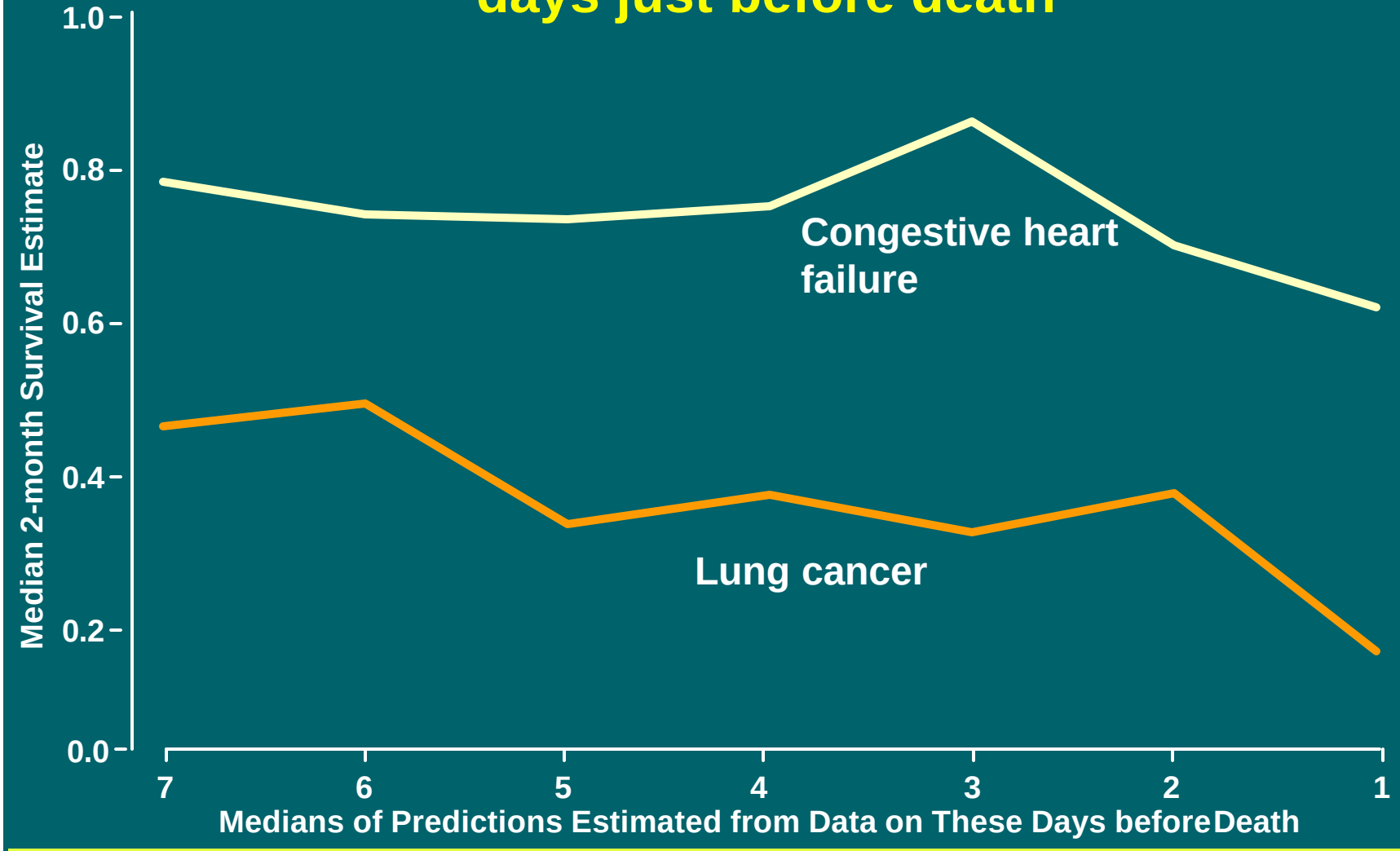
	1900	2000
Age at death	46 years	78 years
Top Causes	Infection Accident Childbirth	Cancer Organ system failure Stroke/Dementia
Disability	Not much	2-4 yrs before death
Financing	Private, modest	Public and substantial- 83% in Medicare ~½ of women die in Medicaid

Challenges in Addressing End to Life (At all)

Fundamental Truths…

1. Dysfunctions from demographics, not doctors.
2. Language, categories, and assumptions
3. Ignoring patients' clear and informed preferences is now uncommon.
4. Quality comparisons do not address fatal illness.

Median likelihood of surviving 2 months, on the days just before death



R Health

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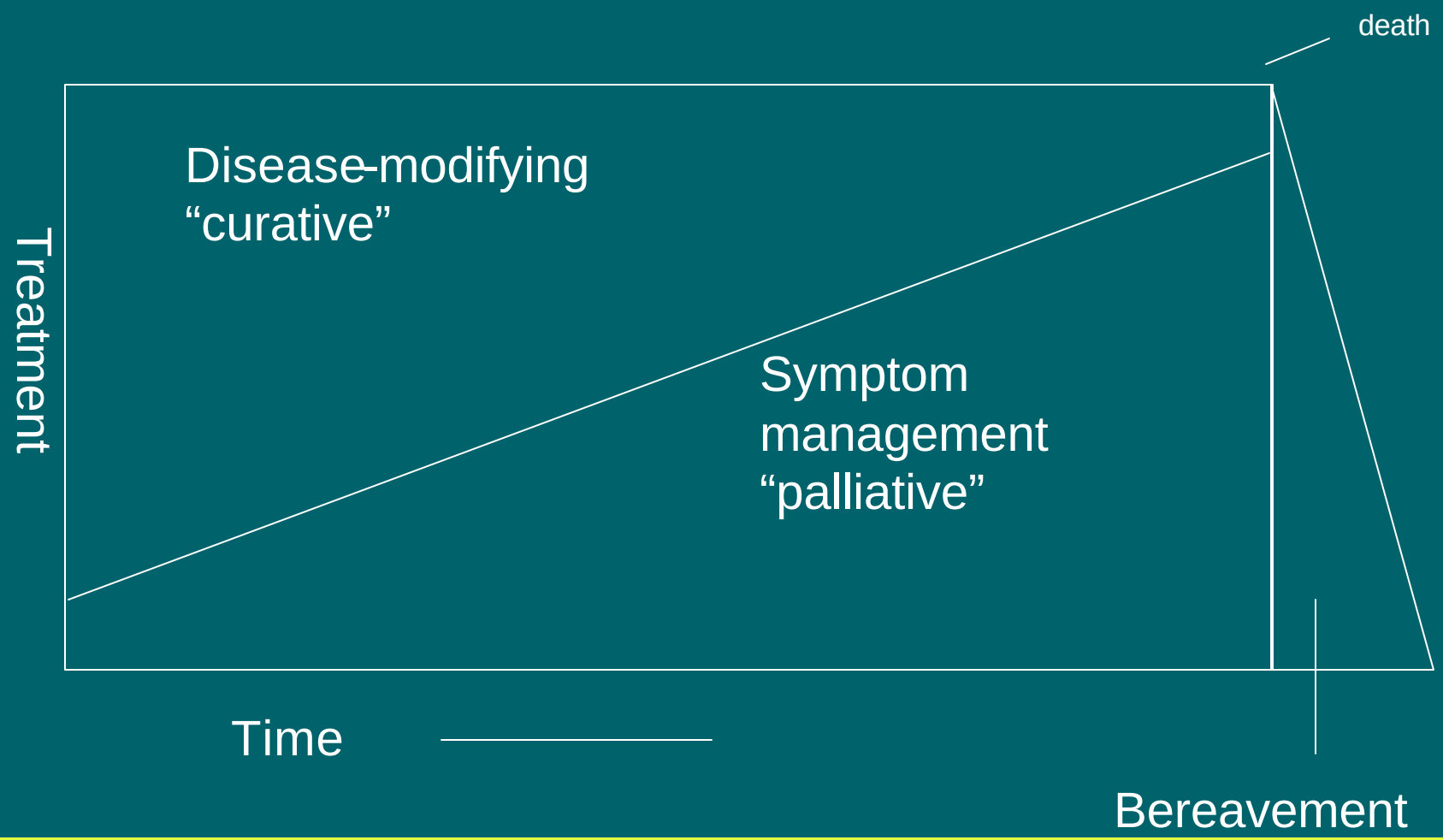
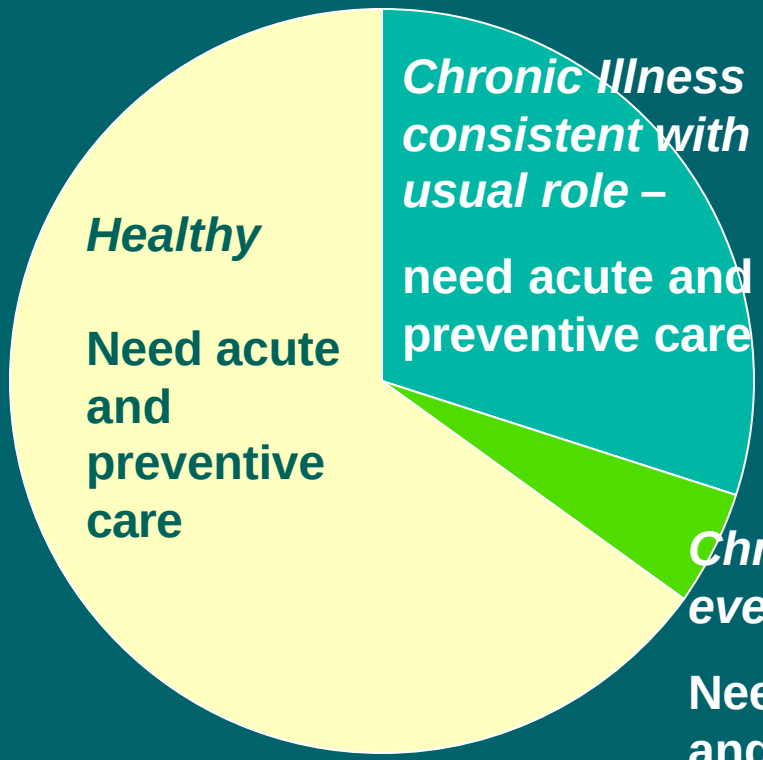
Old Concept

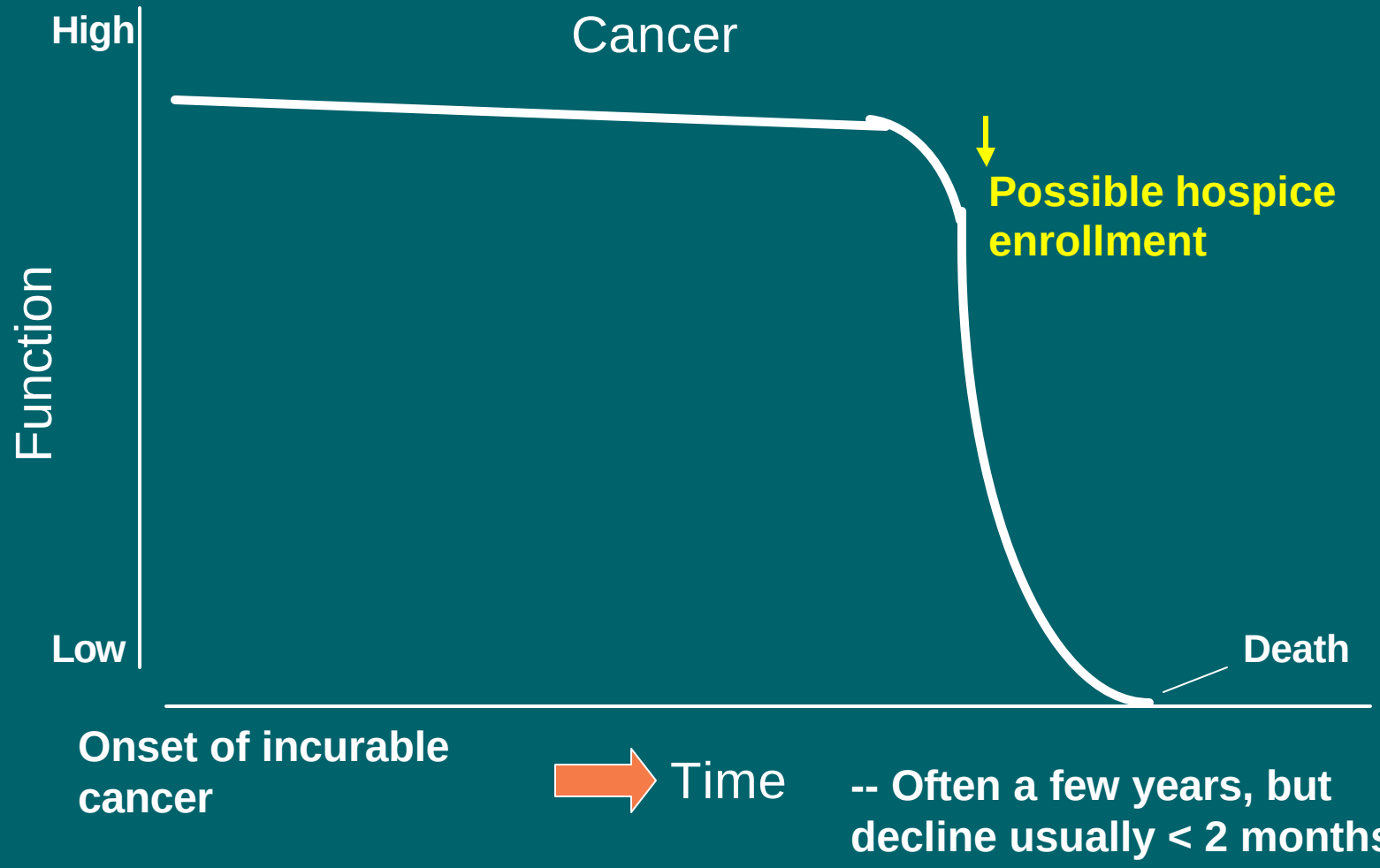
Better Concept



Health Status of the Population (a conceptual model)



“Cancer” Trajectory, Diagnosis to Death



Organ System Failure Trajectory

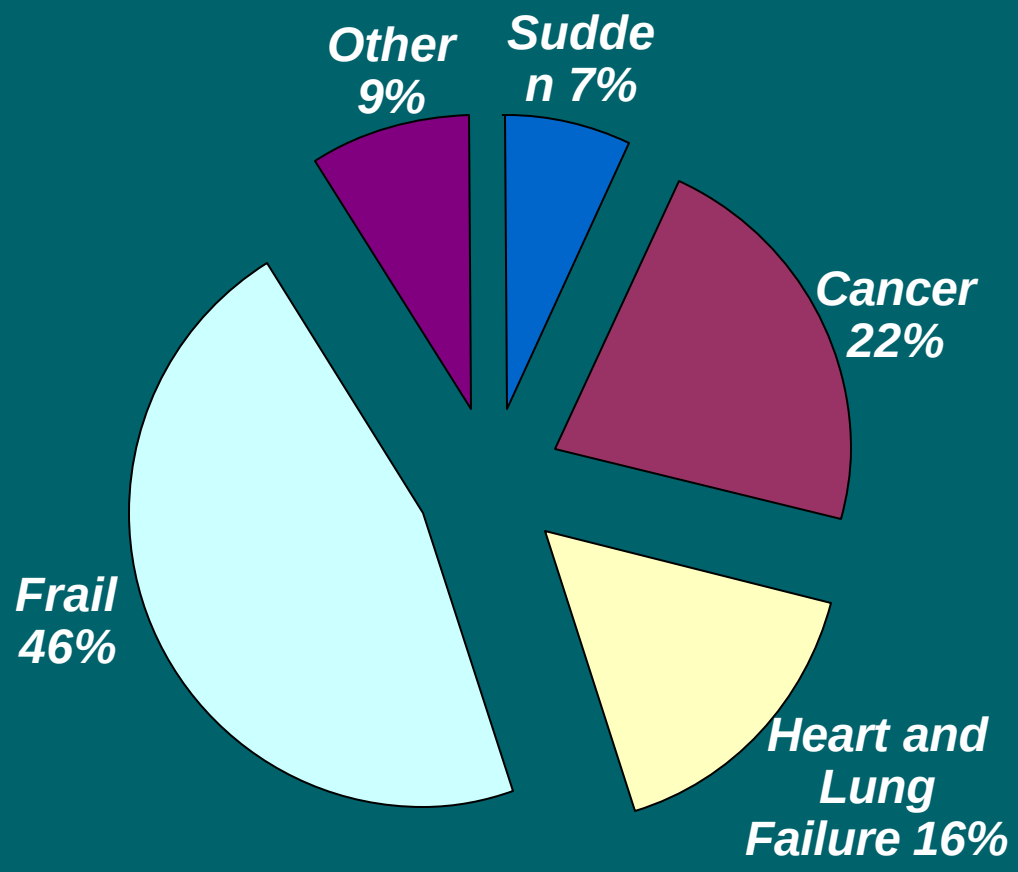
(mostly heart and lung failure)

Begin to use hospital often, self-care becomes difficult

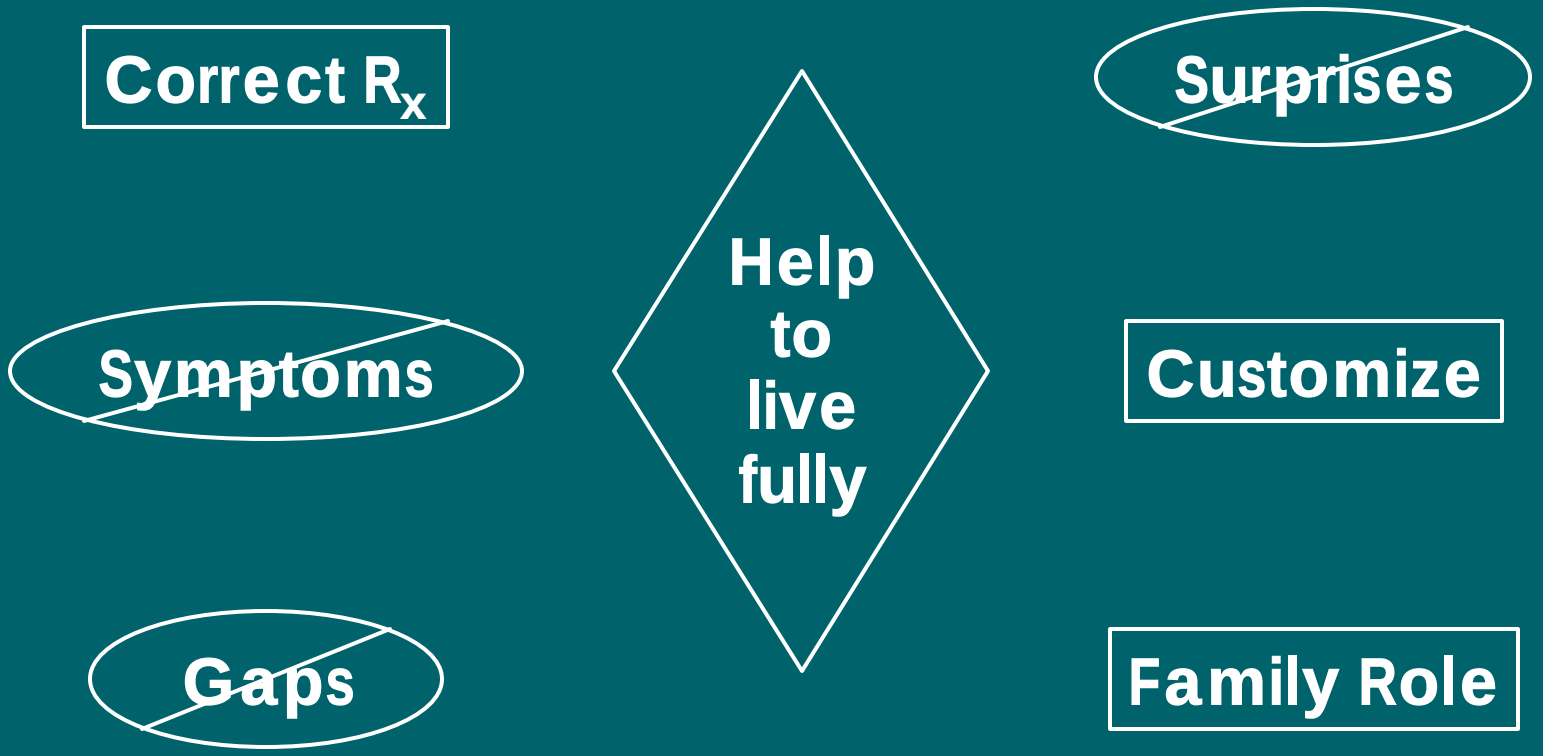
~ 2-5 years, but death usually seems “sudden”

Dementia/Frailty Trajectory

Medicare Decedents



What Good Care Systems Should PROMISE



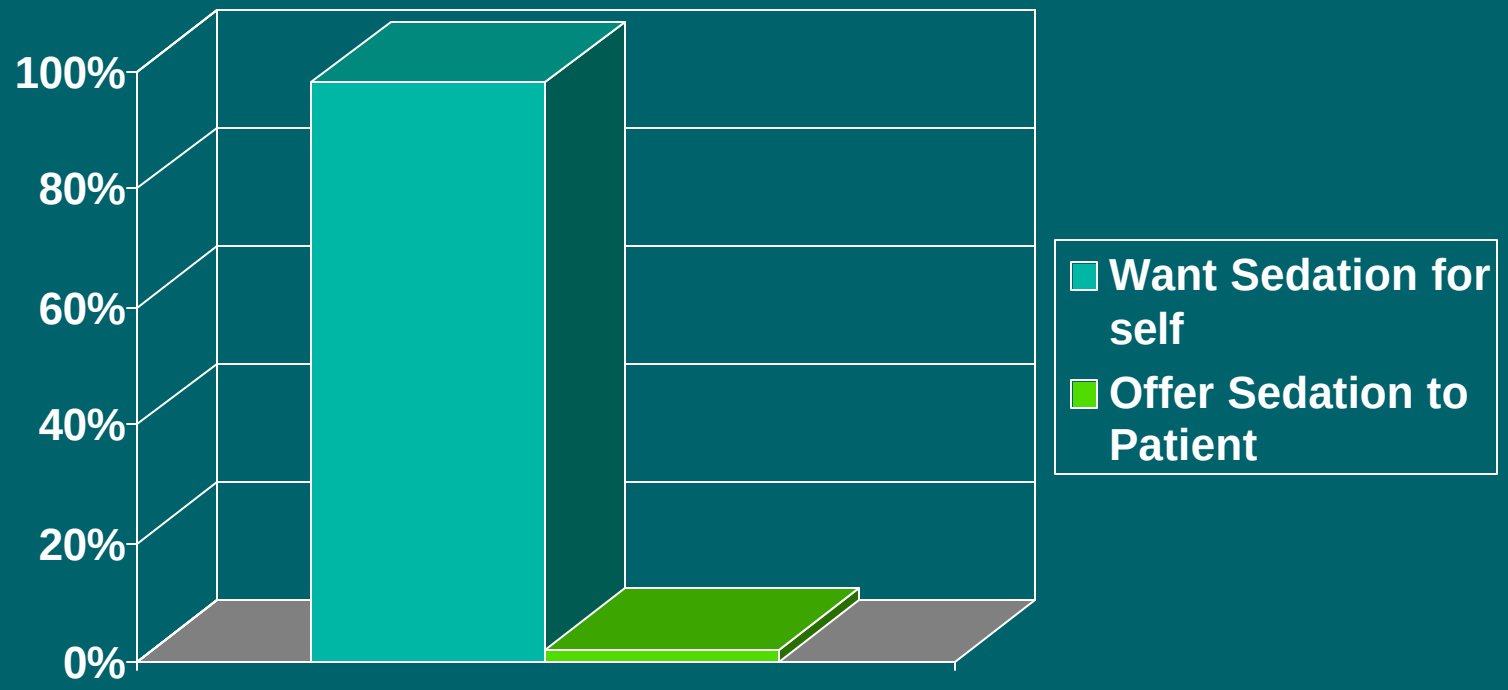
Examples of Current Shortcomings

1. Untreated pain (nursing homes)

2. Advanced care plans

3. Living out life at home.

US Hospitalist Physicians Views on Terminal Sedation



Lynn, Goldstein, Annals Int Med, May 20,2003

Observations on Quality

1. **Most people do not have clear, enduring, and important preferences *about treatment choices***
2. **Best practices are in VA and staff model managed care (not fee-for-service).**
3. **Hospice offers high quality comprehensive care – to 25% of decedents for a median of 25 days.**
4. **Very little innovation or research is underway.**

Observations on Markets in End of Life Care

1. Quality is unmeasured
2. Geographic concentration needed
3. Longitudinal integration needed

More on Markets

4. Various services substitutable
5. Critically important “voluntary” family caregiving.
6. Measures of quality look better with earlier death.

More on Markets

7. People want to *have had* the good death.

8. Small chances of prolonging life keep patients "*wanting to live*."

9. Current payment does not support key elements of chronic care

More on Markets

10. Prevention and treatment are presented as achievable when they are not.

11. We probably now spend more than one-third of all health care on treatments and support for persons who will die with their conditions (eventually) – yet we call it “cure” and “rehab.”

Remaining FTC Questions for this hearing

1. Volume – sensitive quality? No evidence
2. Academic better, trainees worse? No evidence
3. Patients get what they want? If instructions are informed and clear – but that is rare
4. Has Patient Self-Determination Act helped? Not much change, construct was quite legalistic – has led to more clarity on state laws
5. Role of competition? Complex. Usual participant does not want the product, the situation, the information. Better and worse providers are all busy. Patients too sick, and families too stressed to shop carefully. Medicare/Medicaid payment presents barriers.

Orbis Terrarum, 1675 by Visscher