Understanding Dying in America

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Topics

- Prognosis & severity
- How we die
- Advance care planning
- Hospice and palliative care
- Artificial nutrition
- CPR
- Death with Dignity laws
- VSED
- Euthanasia
- Discussing death and dying
- Coping with life-threatening illness

Guiding Principles

- The will of the patient, not the health of the patient, is the ultimate goal of health care.
- Much of medical care is uncertain
- Uncertainty is almost always attended by fear.
- Fear is almost always a factor in decisions in medicine that lead to bad outcomes.

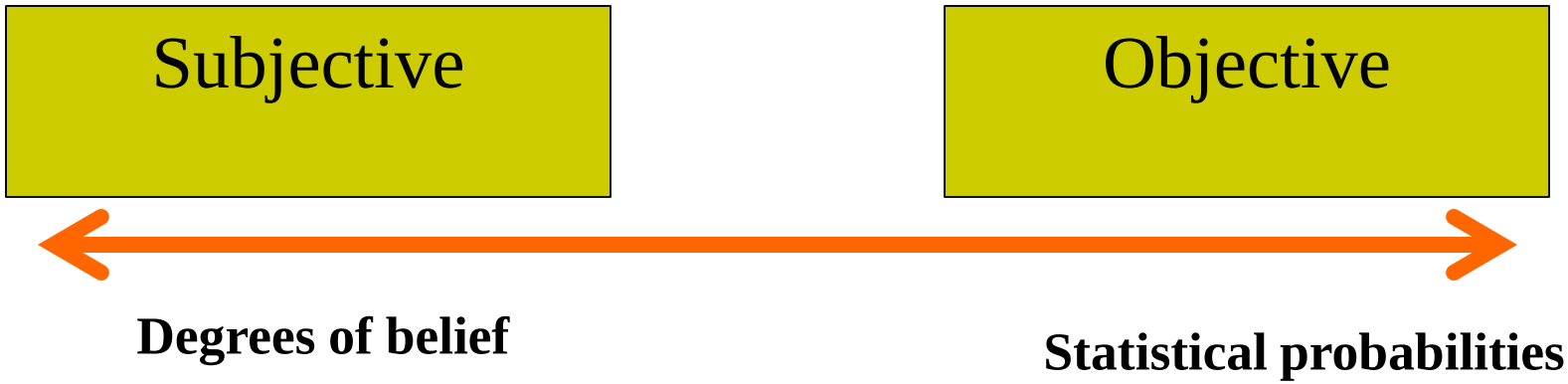
Making a Medical Decision

- Case example – a 87 year old man has advanced non-small cell lung cancer
  - Average survival without chemotherapy is 8.5 months
  - 20% to 40% have a good response to chemotherapy – average survival 15 month
  - 60% to 80% have a poor response to chemotherapy – average survival 7 months

Verma AA, Understanding Choice, JAMA 2014, 311:571-572

Dealing With Uncertainty

- A good medical decision reflects the patient's values, applies scientific evidence, considers medical expertise, and acknowledges uncertainty.
- Different ways of "knowing"



Ways People Make Decisions

- First – we simplify the choice
  - What did you consider - survival, side effects, costs, quality of life
  - Did you also think of the things you have to do regardless of the choice – advance directives, handling personal matters?

An Experiment – Part 1

- Imagine an infectious disease expected to cause 600 people to die
  - Program A has 100% probability of saving 200 people
  - Program B has 33.3% probability that 600 people will be saved and a 66.7%probability that no one will be saved

Which program do you choose?

An Experiment – Part 2

- Same question – an infectious disease is expected to cause 600 to die
  - Program C offers a 100% probability that 400 people will die
  - Program D offers a 1/3 probability that no one dies and a 2/3 probability that 600 people die.

Which program do you choose?

Ways People Make Decisions

- Second – we frame the decision differently
  - The choice between Program A and Program B was framed in terms of "gains" (lives saved)
    - Gain framing
  - The choice between Programs C & D was framed in terms of losses (deaths)
    - Loss framing
- The actual outcomes were the same in all the scenarios

Current State of Health?

- People in good health tend to “loss frame”
  - Disability and death seems remote
  - May not see the value to aggressive interventions
- People in poor health tend to “gain frame”
  - Already live with disability or discomfort
  - More likely to appreciate aggressive life-sustaining interventions (ICU or dialysis)

Ways People Make Decisions

- Third – having simplified and framed our choices, we estimate the overall value of the options
- We tend to attach more weight to proportional differences than absolute differences
  - The difference between 1 death and no deaths (100% reduction)
  - The difference between 1000 and 999 deaths (0.1% reduction)

Populations

- Healthy people and people with acute, time-limited conditions
- People with stable or early chronic conditions
  - Maintain their usual social role and have long life expectancy
- People with serious, progressive, eventually fatal illness
  - Meet the “surprise question” criterion

Lunney JR JAMA 2005;289:2387-2392

New Terminology Needed

- Hospice – focuses on people in the last 6 months of life
- Palliative care – focuses on symptomatic improvement regardless of health status
- Care for those with Eventually Fatal, Chronic Conditions*
  - PACE, some HMOs (SCAN), Sutter AIM, Home Support, Gunderson Lutheran

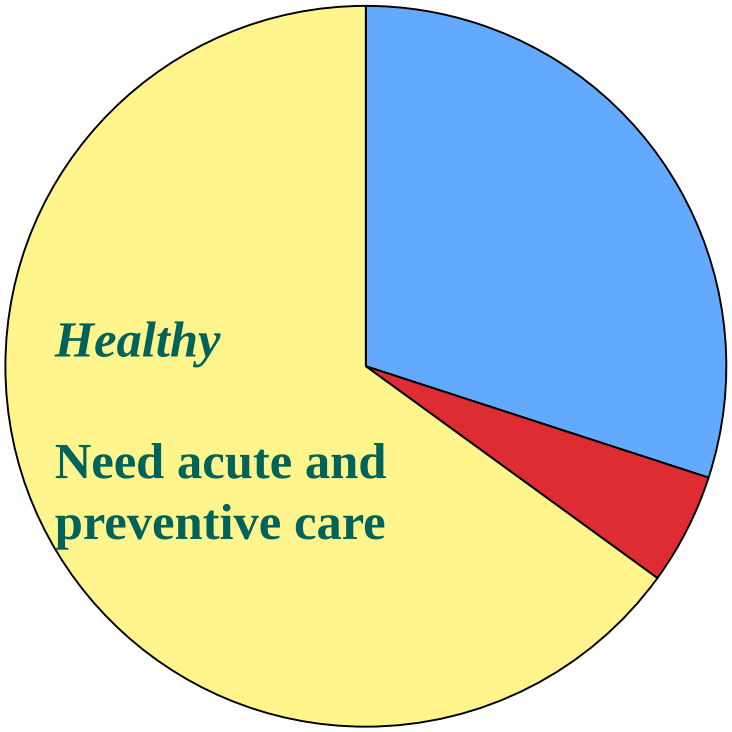
*Joanne Lynn, Sick to Death, 2004

A Century to Get Into Problems

	1900	2010
Age at death	46	80
Top causes	Infection Accidents Childbirth	Cancer Organ system failure Stroke Dementia
Disability	Not much	2 - 4 years before death
Financing	Private, modest	Public (Medicaid and Medicare) Substantial (83% in Medicare, ½ of women in Medicaid

Lynn J, Sick to Death, 2004

Health Status of the Population



Chronic Illness consistent with usual role –

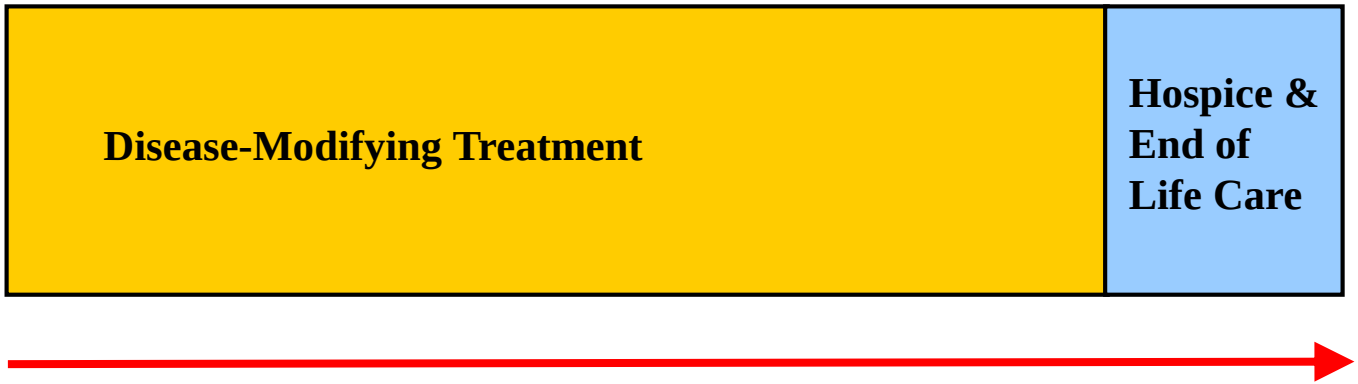
Need acute and preventive care, and education about the future

Chronic, progressive, eventually fatal illness

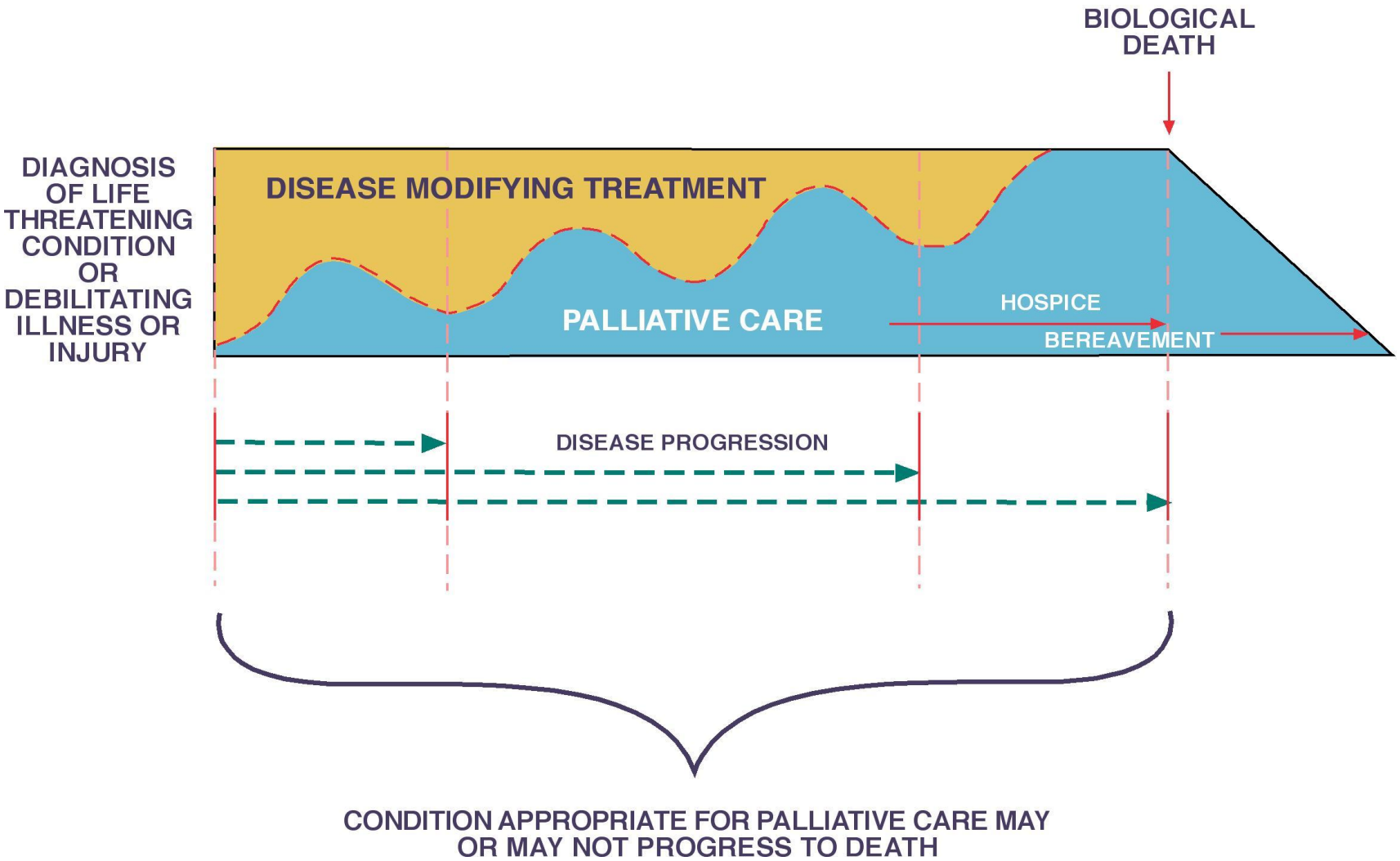
Needs: Different services and priorities. Excellent caregivers

Lynn J, Sick to Death, 2004

The Old Medical Model



The New Model



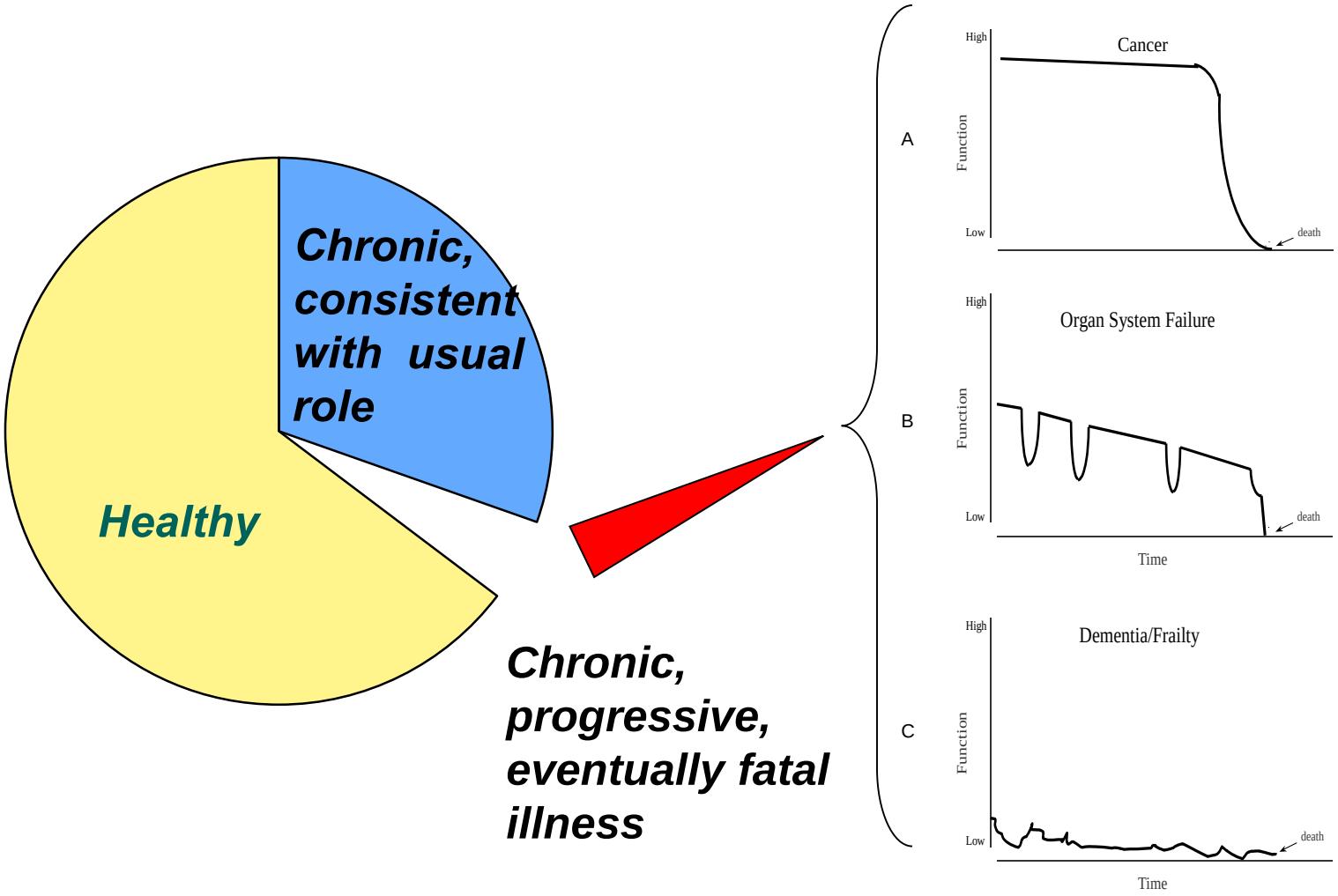
Leading Causes of Death (>65)

1. Heart disease
2. Cancer
3. Chronic lung disease
4. Unintentional injuries
5. Stroke
6. Alzheimer's
7. Diabetes
8. Flu & pneumonia
9. Kidney failure
10. Suicide

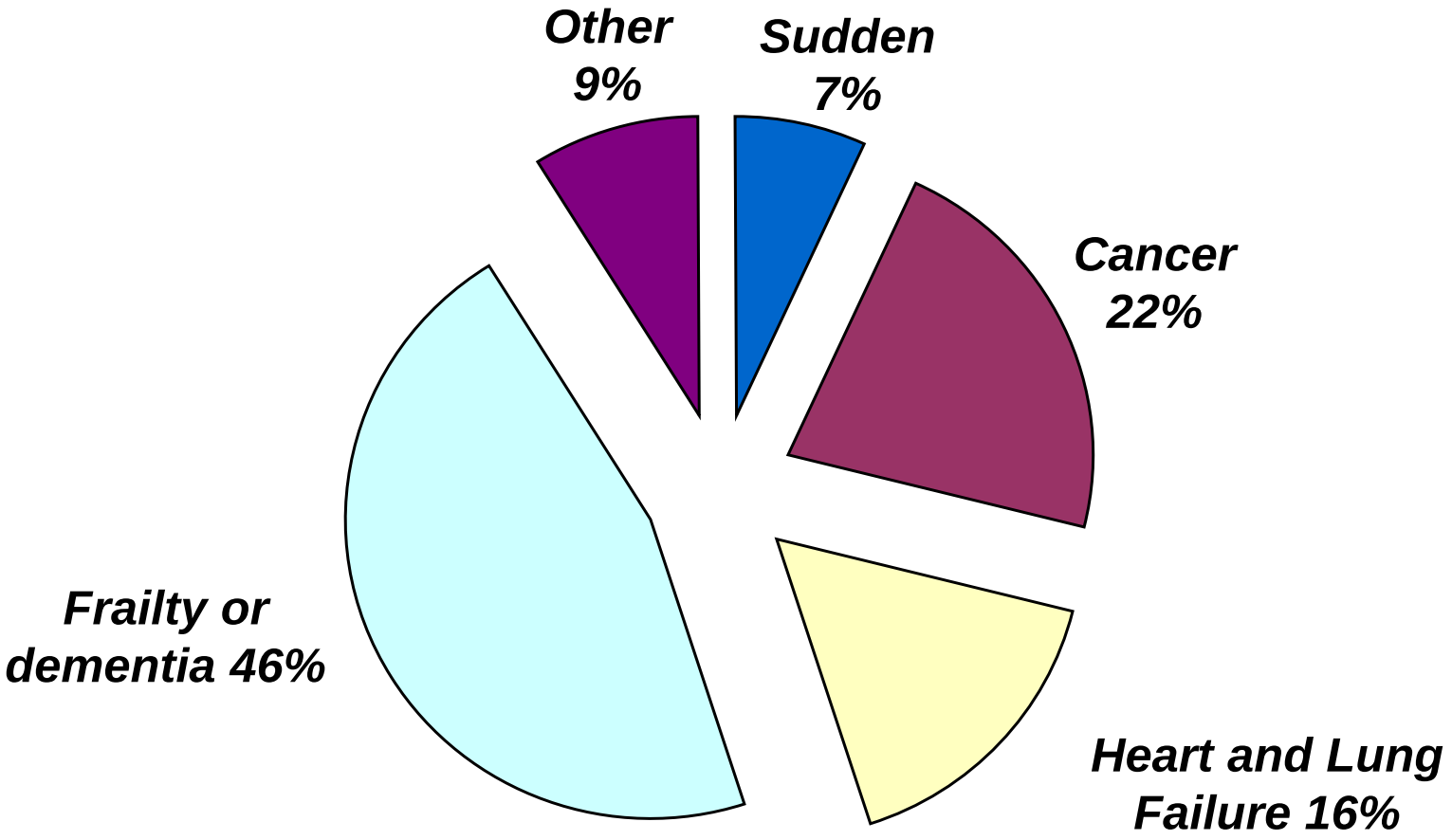
Only two of these are unexpected!

CDC, Health, United States, 2014

Five Percent of the Population



Medicare Decedents



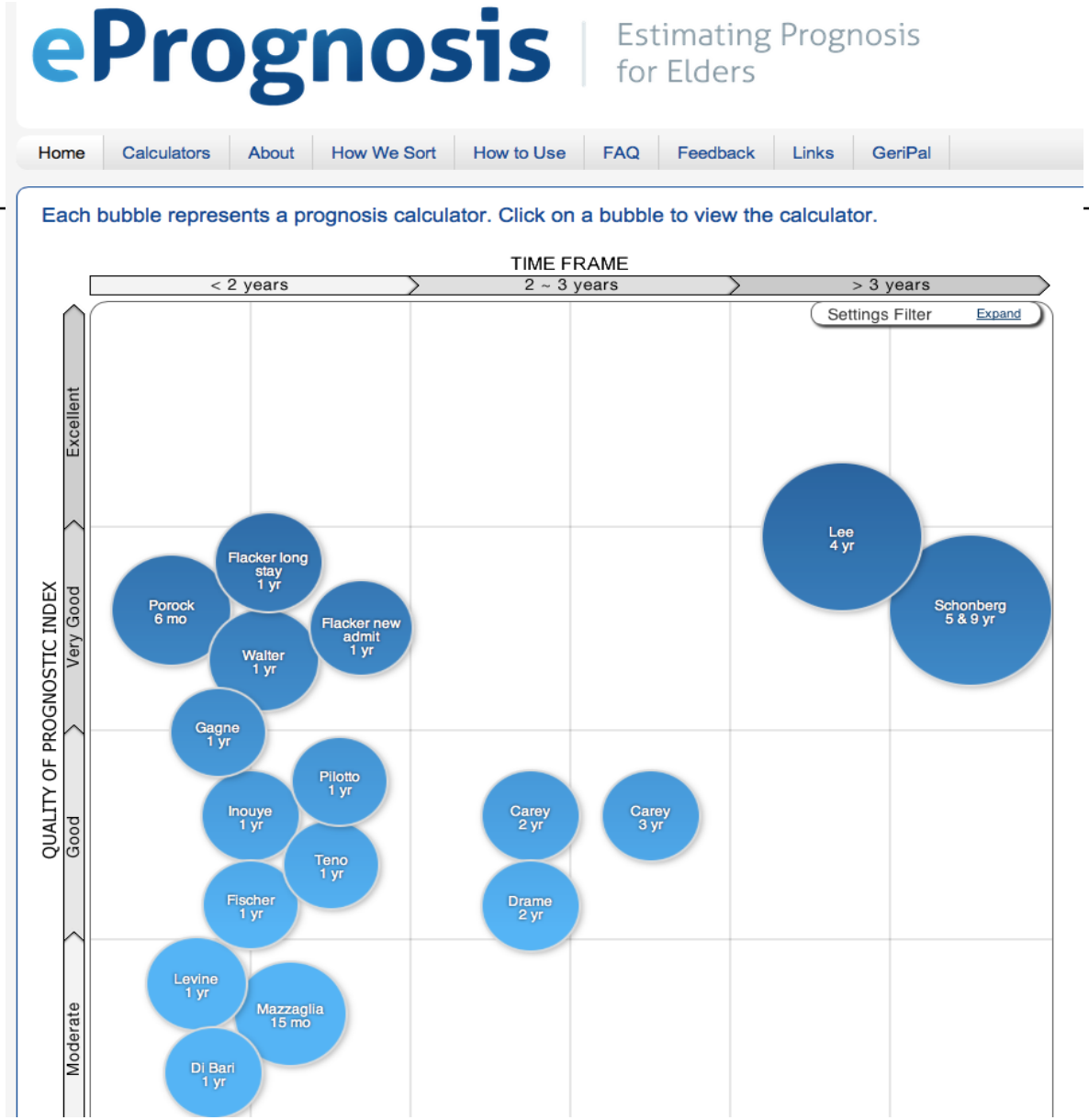
93% of patients have “expected deaths”

Severity vs. Prognosis

- Severity
  - Traditional: severity framed in physiologic terms (FEV1, EF) or functional deficits or age
  - New model – framed in patient's perceived quality of life or goals
- Prognosis
  - Traditional: computed based upon above factors
  - New model: chances that interventions will achieve patient goals

Forced expiratory volume – 1 second

Ejection fraction of the heart



http://eprognosis.ucsf.edu/default.php

What Is Needed To Help People with Eventually Fatal Chronic Conditions?

- “Deep” advance care planning
- A committed, capable team
- A system with options
- Caregiver education and support
- Proper financing
- Respect for patient decision-making

“Deep” Advance Care Planning

- Occurs early in the course
- Repeated and adjusted over time
  - Responsive to change (status or desires)
- Foundation –understanding of and respect for the patient’s goals and wishes
- Courageous – willing to go against standard clinical guidelines and quality measures
- Contemplative – based on reflection

3- Step Process

- Understand the patient's goals and wishes
  - Make sure the caregivers understand and accept them
- Complete advanced care documents
  - Name and educate a surrogate
- Complete a POLST for when the "surprise question" applies

Understanding Goals & Wishes

- What is most important in your life now?
- What experiences have you had with serious illness?
- Which fits your values?
  - Treat intensively even if it means suffering to try to extend life
  - Use medical treatments but stop if you are suffering, even if it means a shorter life
  - Use all measures to promote comfort, even if it means a shorter life
- Can you imagine a health situation that would be worse than death?
- Have you changed your mind about what is important over time?

Goals of Care video

Medical Decisions in EFCC

- Guided by:
  - Patient goals and wishes and
  - Documented in advanced directives
  - Evidence-based outcomes valued by the patient
  - A recommendation by an experienced, compassionate team
- Informed by:
  - Recognition of risk
  - Use of prognostic indicators

What People With EFCC Need

- Relief of medical symptoms
  - Especially pain
- Caregivers who are trained and supported
- Continuity of services and providers
- A safe environment that promotes function
- Help with planning for the future
- Providers who commit to following the patient's wishes
- A quality system that measures these things

Provider Decision-making

- What are this patient's goals?
- Is the treatment I'm considering likely to help the patient reach her goal?
- What harms may come from treatment?
- If we decide not to provide this treatment, what else do I need to do to reduce suffering or enhance quality of life?

Case Example

- 92 year old woman, living in an nursing home dementia unit
- POLST (discussed with son) – DNR, comfort level of care, no artificial nutrition
- Found unconscious, aide called 911 before checking chart, patient transported to hospital
- Heart rate 220. Treated and HR now 86. Resident is now awake and alert.
- What next?

Slow Medicine Principles

- Understand the person deeply, acknowledging both losses and strengths
- Accept the need for interdependence and promote mutual trust
- Communicate well and with patience
- Make a covenant for steadfast advocacy
- Maintain an attitude of kindness no matter what

Dennis McCullough, *My Mother, Your Mother*, 2008

Recommended Resources

- *Being Mortal*, Atul Gawande
- *Sick to Death*, Joanne Lynn
- *My Mother, Your Mother: Embracing Slow Medicine*, Dennis McCullough
- *How We Die*, Sherwin Nuland
- *On Death and Dying*, Elizabeth Kubler-Ross
- *Dying Well*, Ira Byock
- *Dying in America*, Institute of Medicine, free download at: http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx