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

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”

  - Subjective
  - Objective

  Degrees of belief: Statistical probabilities
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

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

Disease Progression

Disease-Modifying Treatment

Hospice & End of Life Care
Our Model of Care

The New Model

- **Diagnosis of Life Threatening Condition or Debilitating Illness or Injury**
- **Disease Modifying Treatment**
- **Palliative Care**
- **Hospice**
- **Bereavement**

**Condition Appropriate for Palliative Care May or May Not Progress to Death**
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

Chronic, consistent with usual role

Chronic, progressive, eventually fatal illness

Healthy

Cancer

Organ System Failure

Dementia/Frailty

Five Percent of the Population
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
Each bubble represents a prognosis calculator. Click on a bubble to view the calculator.
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