

Trajectories of Dying: *There's more than one way to go.*

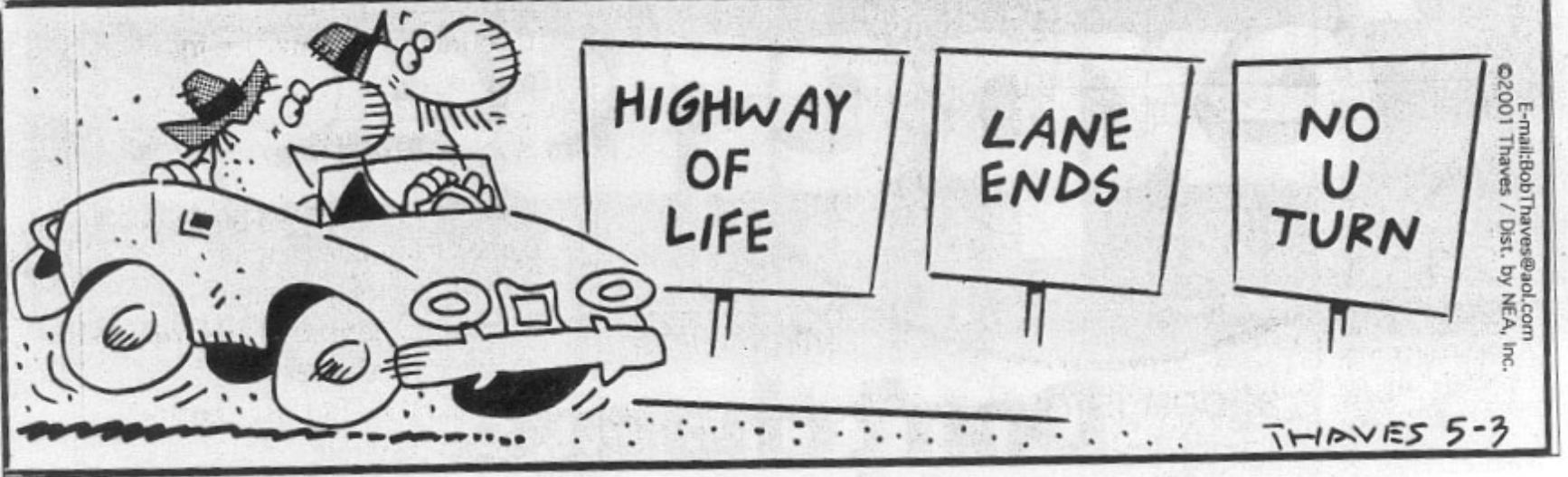
Science and Theology Seminar

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How Americans Die: a century of change

	<u>1900</u>	<u>2000</u>
Age at Death	46	77
Top Causes	Infection	Heart Disease
	Accident	Cancer
	Childbirth	Stroke

Hospice in the US

- **1974** **Connecticut Hospice opens**
- **1982** **Medicare Hospice Benefit**
- **1984** **31 Medicare-certified Hospices**
- **2005** **4,100 Medicare-certified programs**
 1.2 million patients

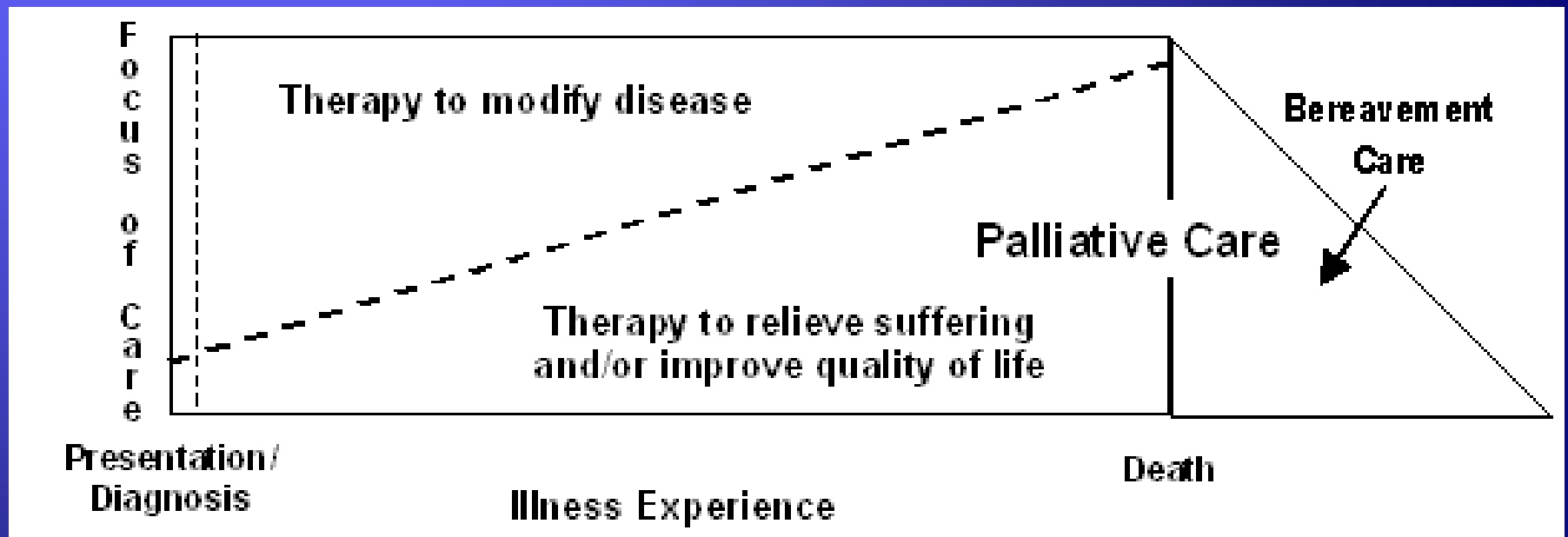
Limitations of hospice care at end of life

- **Not everyone experiences a distinct period of terminal decline**
- **Hospice benefit requires it**
- **Patients and families expect it**

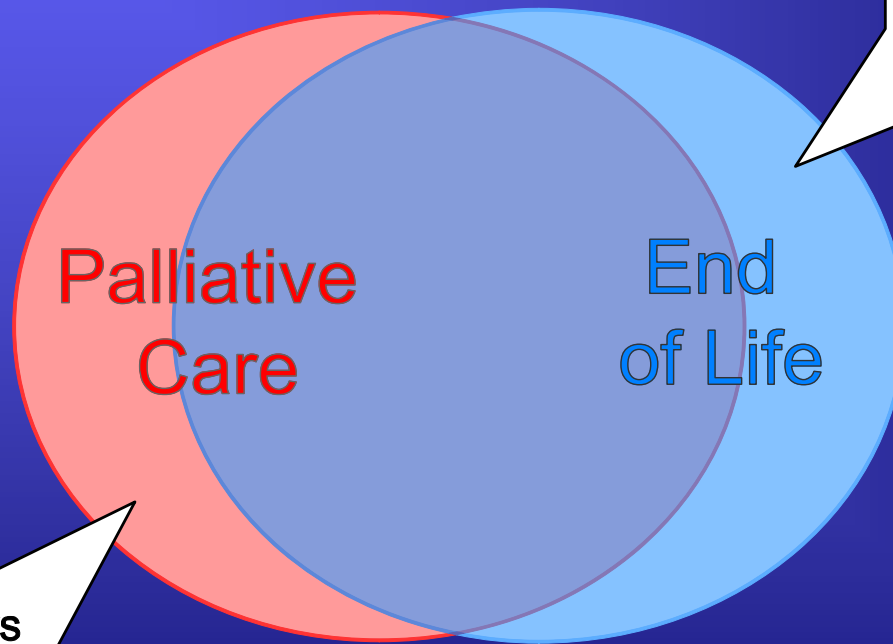
Palliative Care

- **Care devoted to achieving the best quality of life**
- **Through the relief of suffering and control of symptoms**
- **Throughout the course of life threatening illness**

Model of Palliative Care



Palliative Care



Frail Elders Without
Diagnosed Life
Threatening Illness

Eventual Survivors
of a Life
Threatening Illness

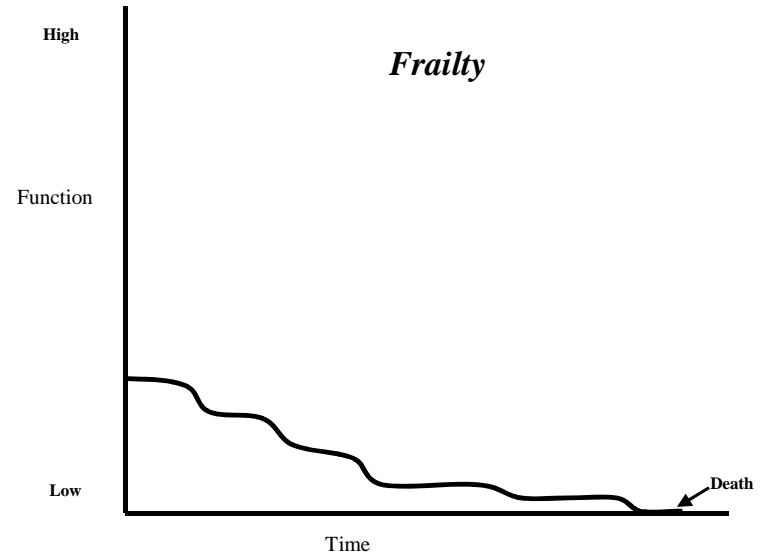
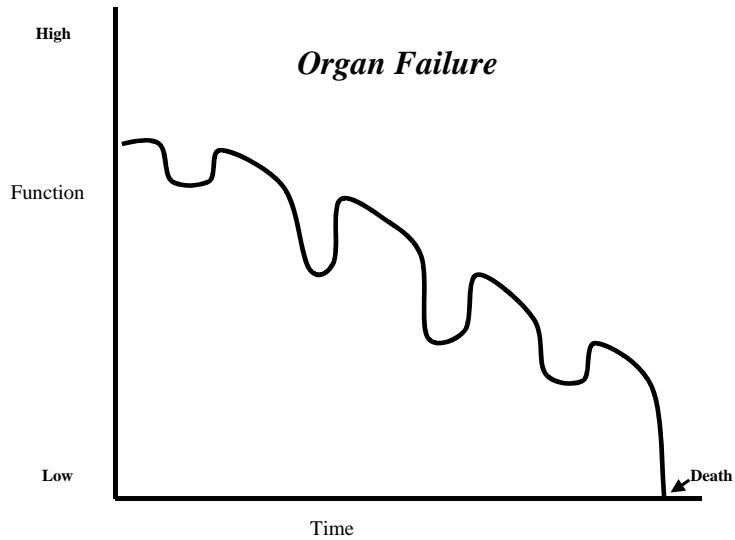
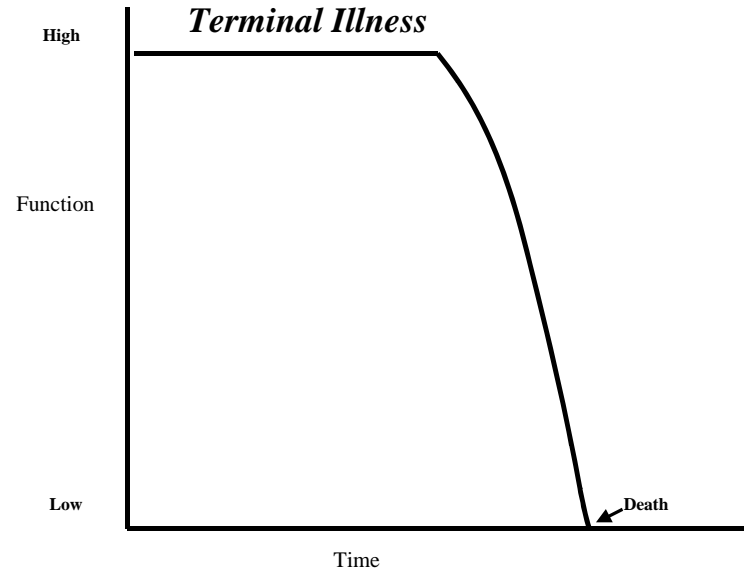
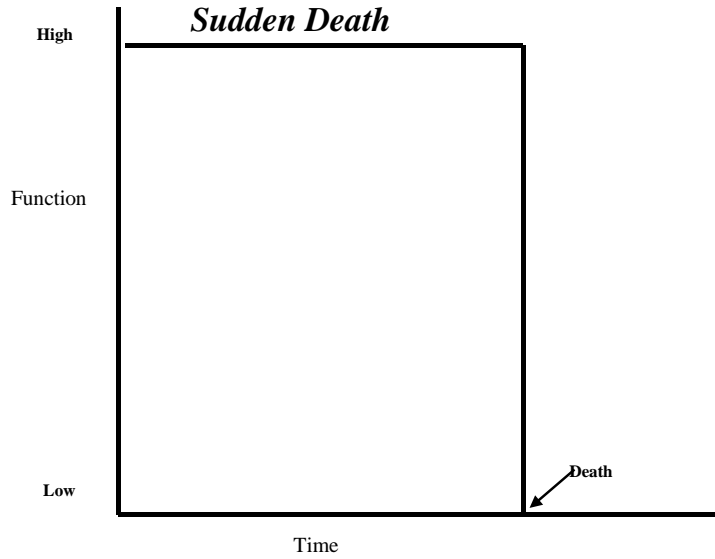


Glaser & Strauss 1968

Dying Trajectories

- **Unexpected Death**
- **Expected Death**
 - **Short term reprieve**
 - **Suspended sentence (lingering)**
- **Entry-reentry Death**

Proposed Trajectories of Dying



Profiling with Medicare claims data

- **0.1% random sample from all Medicare claims from 1993-1998**
 - **~ 36,000 beneficiaries**
 - **~8,000 deaths**
- **Variables: care episodes, procedures, diagnoses, demographics**

Operationalizing the Trajectories

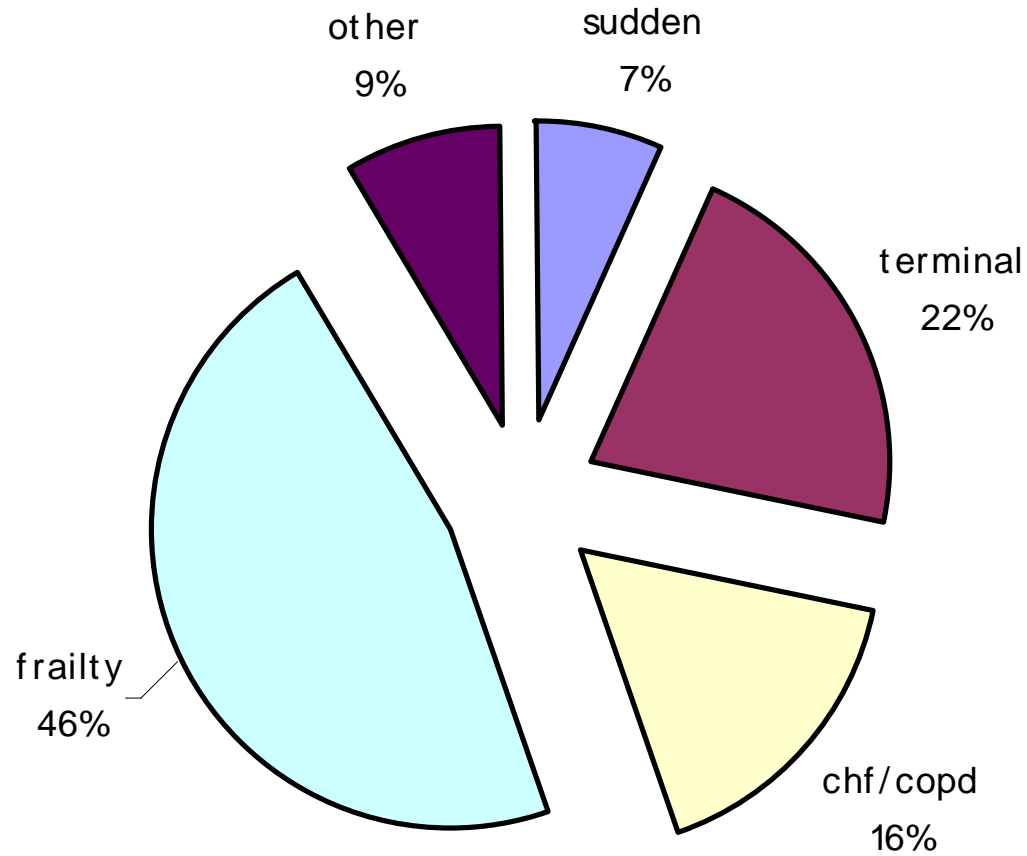
Sudden Death: under 80 years old; <\$,2000 Medicare expenses LYOL

Terminal Illness: cancer was the most common diagnosis on claims for physician services LYOL

Organ Failure: a claim in LYOL for an inpatient stay or ER visit with a discharge diagnosis of CHF or COPD

Frailty: any claim in LYOL containing one of the following diagnoses: stroke, Alzheimer's Disease or other dementia, Parkinson's Disease, delirium, hip fracture, incontinence, pneumonia, dehydration, leg cellulitis, syncope

Distribution of Decedents (n=7258)



Data matched ideas

Demographics:

- **Age progression:
sudden (73) to frail (83)**
- **Gender differences:
+men sudden and
+women frail**
- **Racial difference:
+minorities sudden**

Costs:

- **Hospice use by terminal**
- **Nursing home use by
frail**
- **High cost with organ
failure**

**But what about
functional decline?**

EPESE

Established Populations for Epidemiological Studies of the Elderly

- **Four sites**
 - **East Boston, Massachusetts**
 - **Washington & Iowa counties, Iowa**
 - **New Haven, Connecticut**
 - **5 counties of North Central North Carolina**
- **14,456 study participants**
- **Data collection: 1981-1997**
- **Baseline in-person interview**
- **Six annual telephone follow-up interviews**

Measures

- **Physical function**
 - **Activities of Daily Living**
 - **Mobility**
 - **Performance**
- **Cognitive function**
- **Self-reported chronic conditions**
- **Hospitalizations, nursing home admissions**

Decedent Sample

4190 decedents who were interviewed
within one year prior to death

Created 12 cohorts
based on interval
between last data and
death

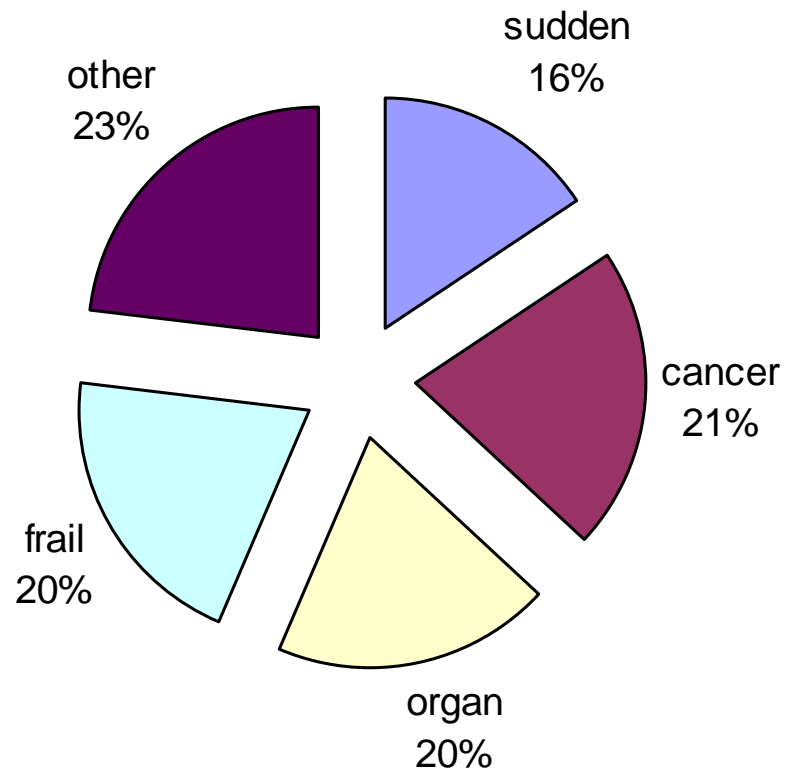
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2	329
3	309
4	341
5	343
6	393

mos	N
7	362
8	372
9	356
10	401
11	353
12	315

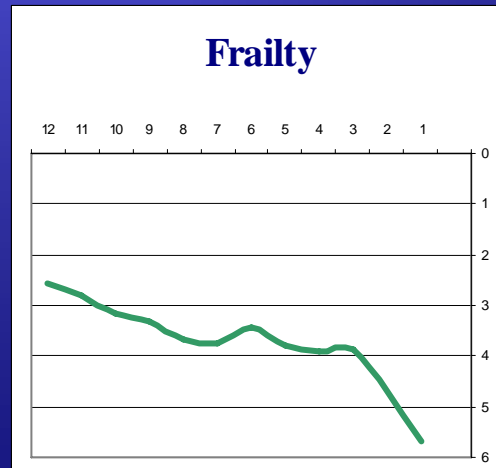
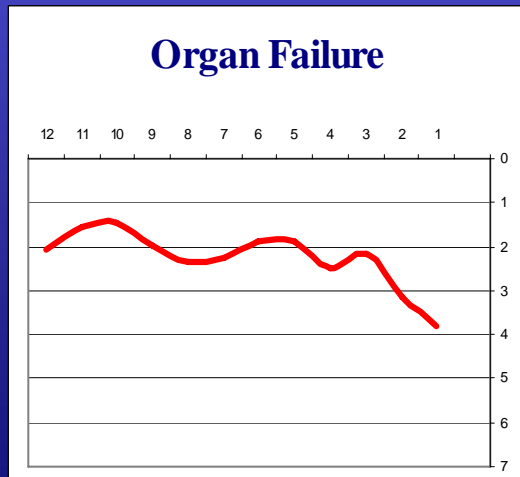
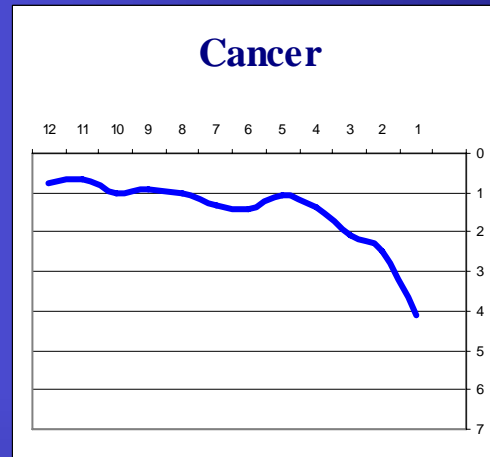
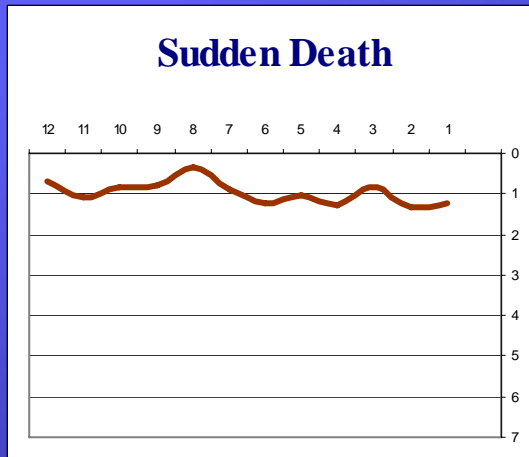
Grouping Decedents

- **Cancer:** any cancer as immediate or underlying cause of death
- **Organ failure:** CHF, COPD or other chronic lung disease noted on death certificate
- **Frail:** spent time in a nursing home
- **Sudden:** not cancer, organ failure or frail and no self reported chronic condition

Decedent Groups (when sequentially identified)



Mean ADL Dependency by Decedent Group



So what?

Implications for Personal Care Needs

- **Sudden Death:** *everyone's dream*
- **Cancer:** *short but intense*
- **Organ Failure:** *unpredictable;
intermittent*
- **Frailty:** *long period of dependency*

Implications for Advance Care Planning

- **Sudden Death:** *you just never know*
- **Cancer:** *develop boundary definition*
- **Organ Failure:** *so what if, then.....*
- **Frailty:** *plan a soft landing*

Implications for Service Delivery

Sudden Death: *not much involvement*

Cancer: *a more seamless transition to palliative care and hospice*

Organ Failure: *good case management, 24hr hotline, enhanced supportive services*

Frailty: *enhanced supportive services*

Personal Care

Planning for disablement

Prevalence of Disability

only tells part of the story

- **Adults who are limited in any activities because of physical, mental, or emotional problems (BRFSS) 18.6%**
- **Older adults (>65 yr) with limitation in self care (Census 2000) 9.5%**

Risk of ADL Disability in the Last Year of Life

(once 65 years old)

- **69% risk of being disabled for at least the last month of life**
- **51% risk of 6 months disability**
- **45% risk of disability for the last full year of life**

Likelihood of Needing Personal Care*

73% risk in last month of life

53% risk for last year of life

**any ADL disability
or mild cognitive impairment*

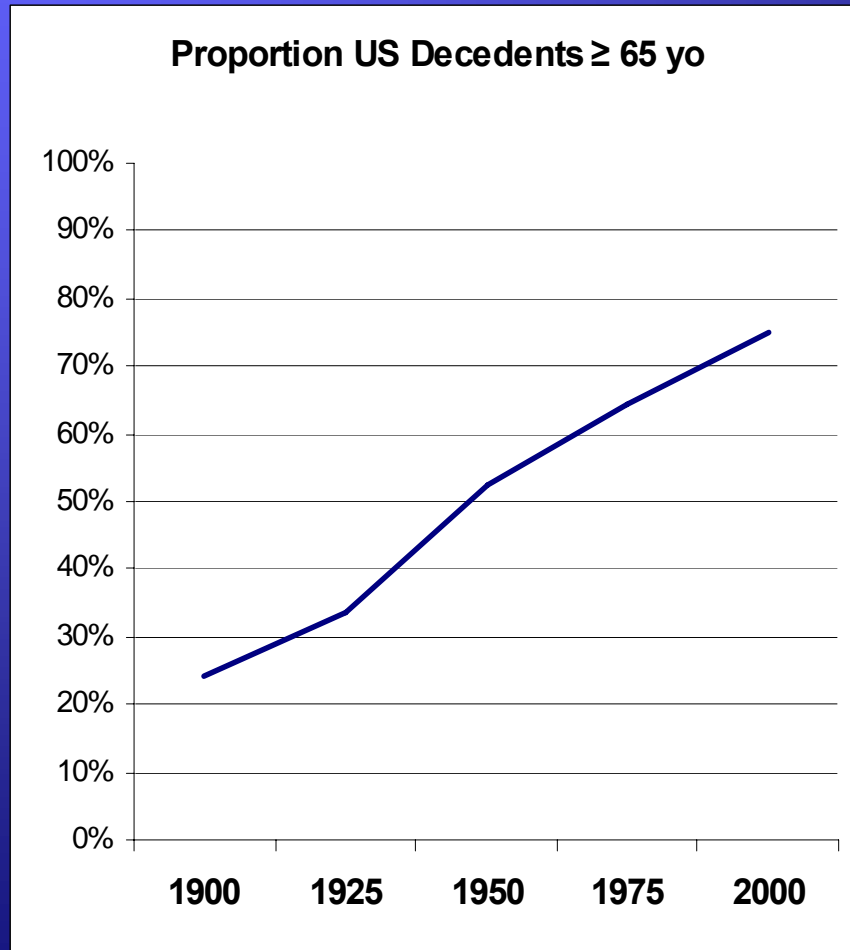
Likelihood of Needing Nearly Constant Care*

61% risk in last month of life

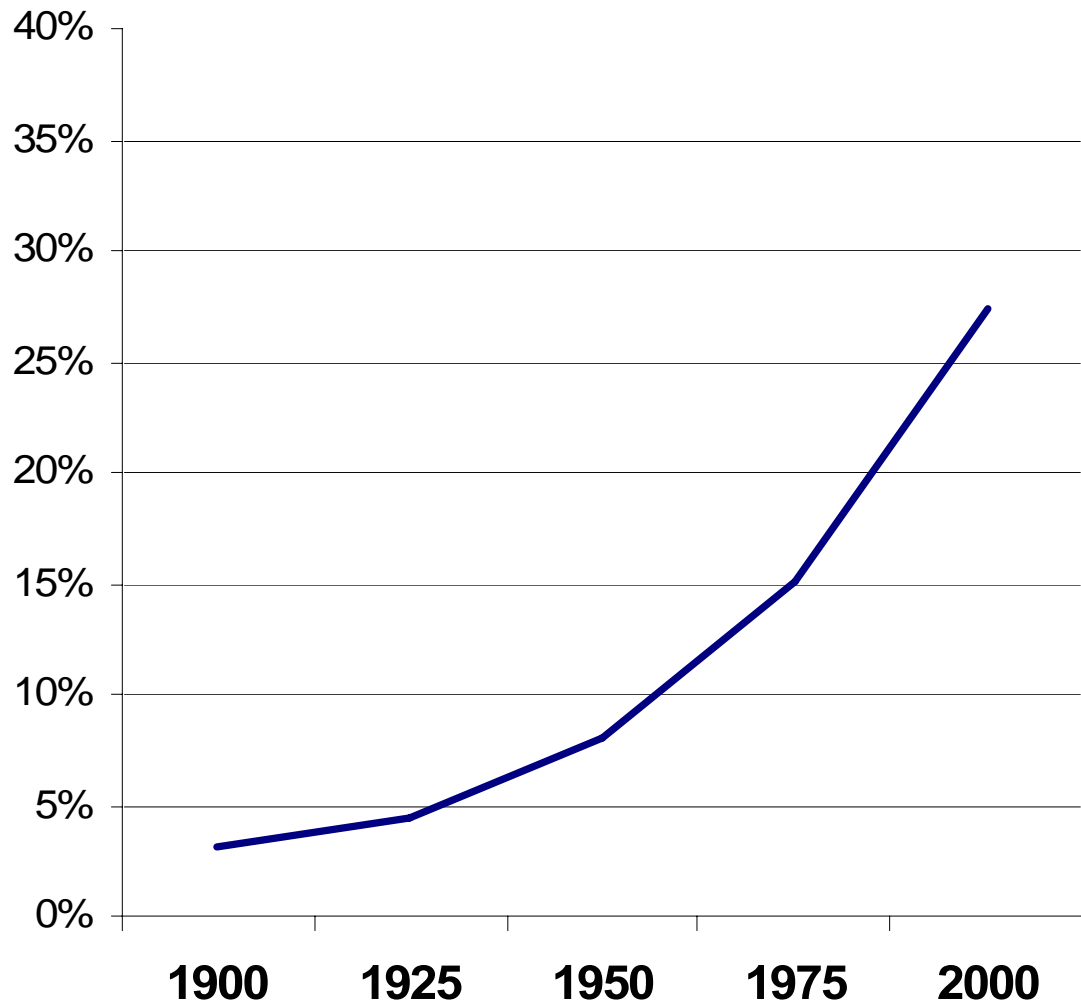
34% risk for last year of life

**Unable to transfer or toilet independently
or having severe cognitive impairment*

Aging of Decedents



Proportion US Decedents ≥ 85 yo



Research

always begets more questions

- **Original interest: changes in physical function**
- **Grew to include changes in cognitive function**
- **Interrelationship and impact on personal care and decision making**

Current focus

“followback” surveys

Can next-of-kin recall and report ...

- Changes in physical function
- Changes in cognitive function
- Decisions faced and choices made

Preliminary findings

Physical function

- *Next of kin don't always know*
- *Recollection intertwined with image*
- *Drawings match verbal descriptions*

From the qualitative data

Decision making

- Sources of distress
- Complexity of dynamics

When to stop trying ?

- **86 yr old mother died in nursing home**
- **Severe dementia throughout last years of life**
- **Pureed food for nine months**
- **BUT good care/ good quality of life**
- **Siblings struggled with potential decisions regarding tube feeding and antibiotics**
- **Frequent hospitalizations**

Hard to “let” parent stop trying

- 96 yr old man had a very gradual decline
- Lost appetite and interest in activities
- Hard to separate out roles of physical frailty, cognitive decline and possible depression
- Visited MD on Friday but declined hospitalization
- Died sitting in chair waiting to go for blood transfusion on Monday
- Both son and daughter angry with father for giving up on life

Limited window of opportunity

- 73 yr old man with “stomach and liver cancer”
- Normal in October, first symptom in November, consulted MD in December, diagnosed in January, dead in February
- Non-conversant almost immediately after diagnosis
 - ?? *physical weakness, quiet personality, psychological meltdown, disease chemistry drug side effect??*

Previous experiences influence

- **Death of mother-in-law within one year of mother's death**
- **Mother died of cancer under hospice care**
 - **No food or fluids last 45 days of life**
 - **attributed non-responsiveness to morphine**
- **Mother-in-law died with dementia**
 - **Guilt about encouraging the fluids that were aspirated**
 - **Guilt about slow response with Roxinal**

Sibling Differences

- **Son still struggling after three years**
- **Differences in siblings' readiness for hospice care**
- **Religion/spirituality differences**
- **Financial disagreements: parents' nest egg spent on caregiving**

Decision Making at the End of a Long Life

- **Is hard work for everyone involved**
- **Rests on individual AND family values**
- **Is an ongoing process not an event**
- **Is not just about life sustaining treatment**
- **Re-examination can continue long after death**

Decision Capacity

- **Understanding**
- **Appreciation**
- **Reasoning**
- **Expression of Choice**

Neuropsychological Components of Capacity

- Orientation
- Attention
- Expressive language
- Receptive language
- Short term memory
- Delayed memory
- Abstraction
- Judgment
- Executive Function
- Spatial Construction

“Normal” Age-related decline in Cognitive Function

- **Decline in effortful information processing**
 - **Processing speed**
 - **Working memory capacity**
- **Loss of ability to inhibit attention to irrelevant information**

Decision Making

- Capacity
- Quality
- Mode

Decision Quality

Aim: outcome matches goal

Need: match of decision to “real” need

Aggregate outcomes: meeting one aim
but accompanied by undesirable
outcomes

Competitor: a better option comes along

Process cost: time, effort and aggravation
associated with making the decision

Decision Mode

Analytic: effortful reasoning

Rule based: deliberately match representation of current situation to previous experience or education

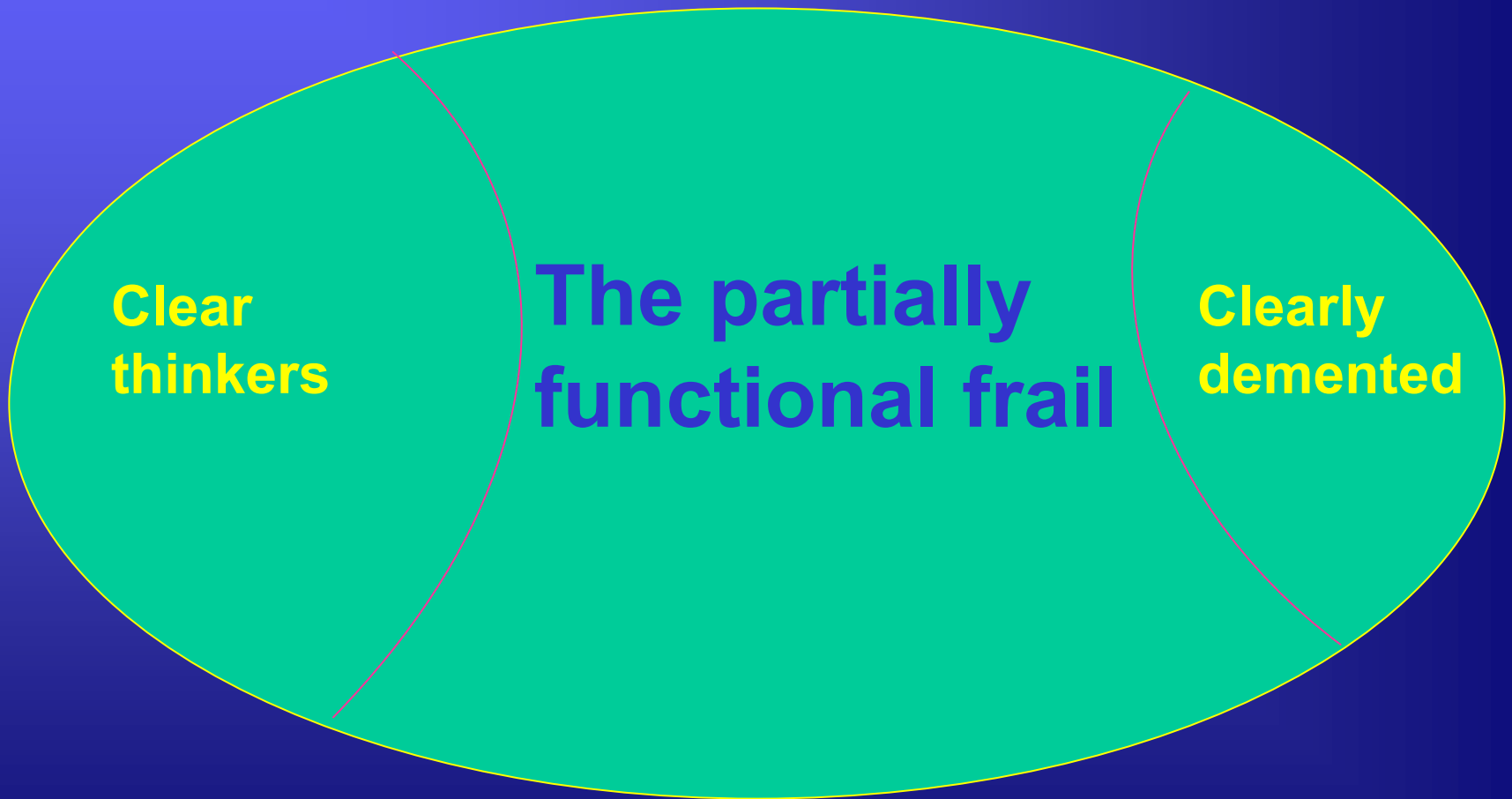
Automatic: match occurs almost unconsciously

Agency: yet another mode ?

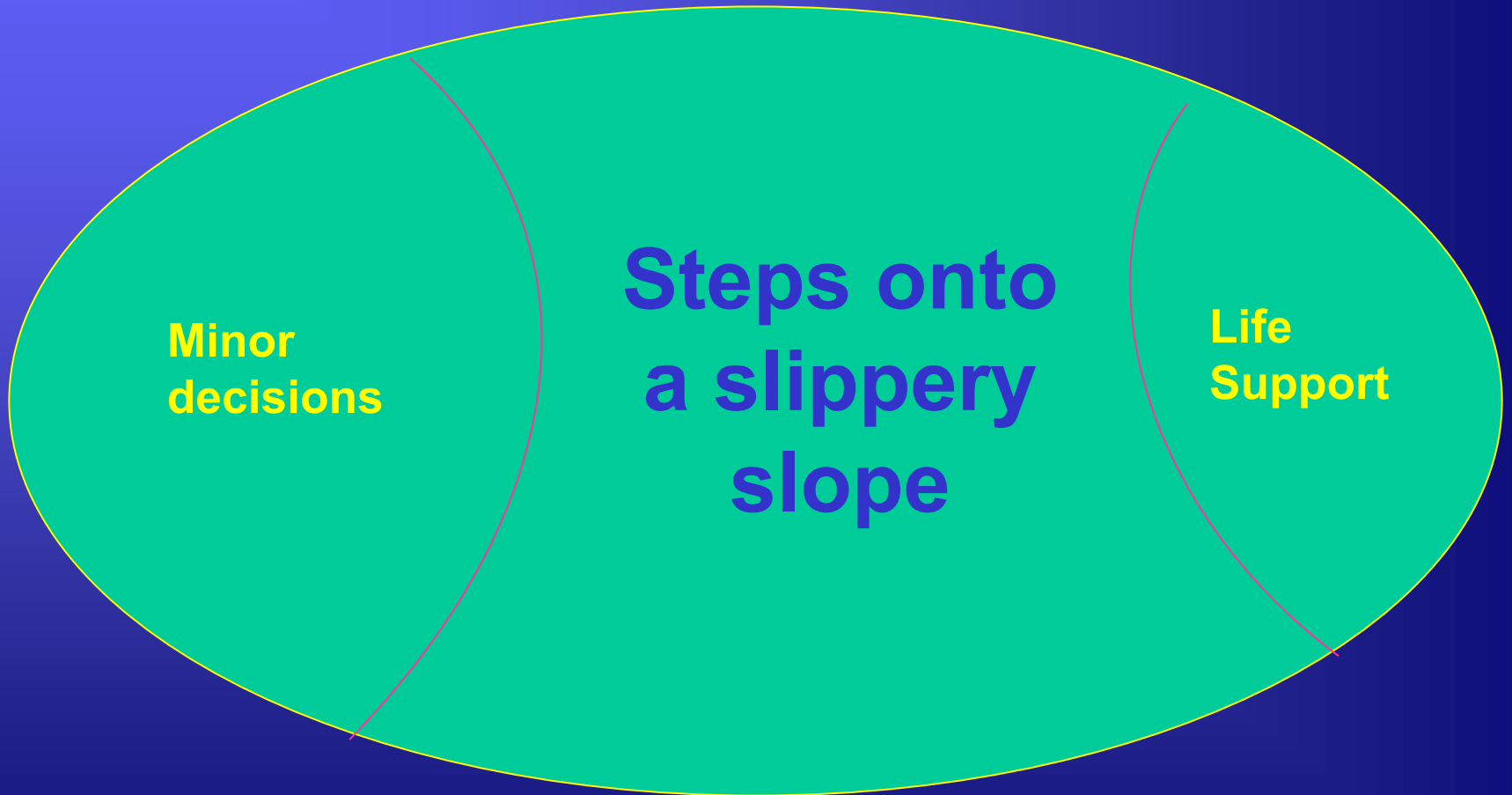
Older adults seem more inclined to call upon decision agents

- Possible cohort reliance on physicians
- Older adults tend to have higher “powerful other” scores on locus of control scales
- Older adults may sense diminishing of their decision skills
- Even with capacity, older adults may choose not to expend the effort
- Older adults may act on an appreciation of the consequences their choices have for family members

Elder Decision Makers



Healthcare Decisions



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