Advanced Stage Dementia and Palliative Care

2013 NIH/ACL Alzheimer's Webinar Series

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Welcome

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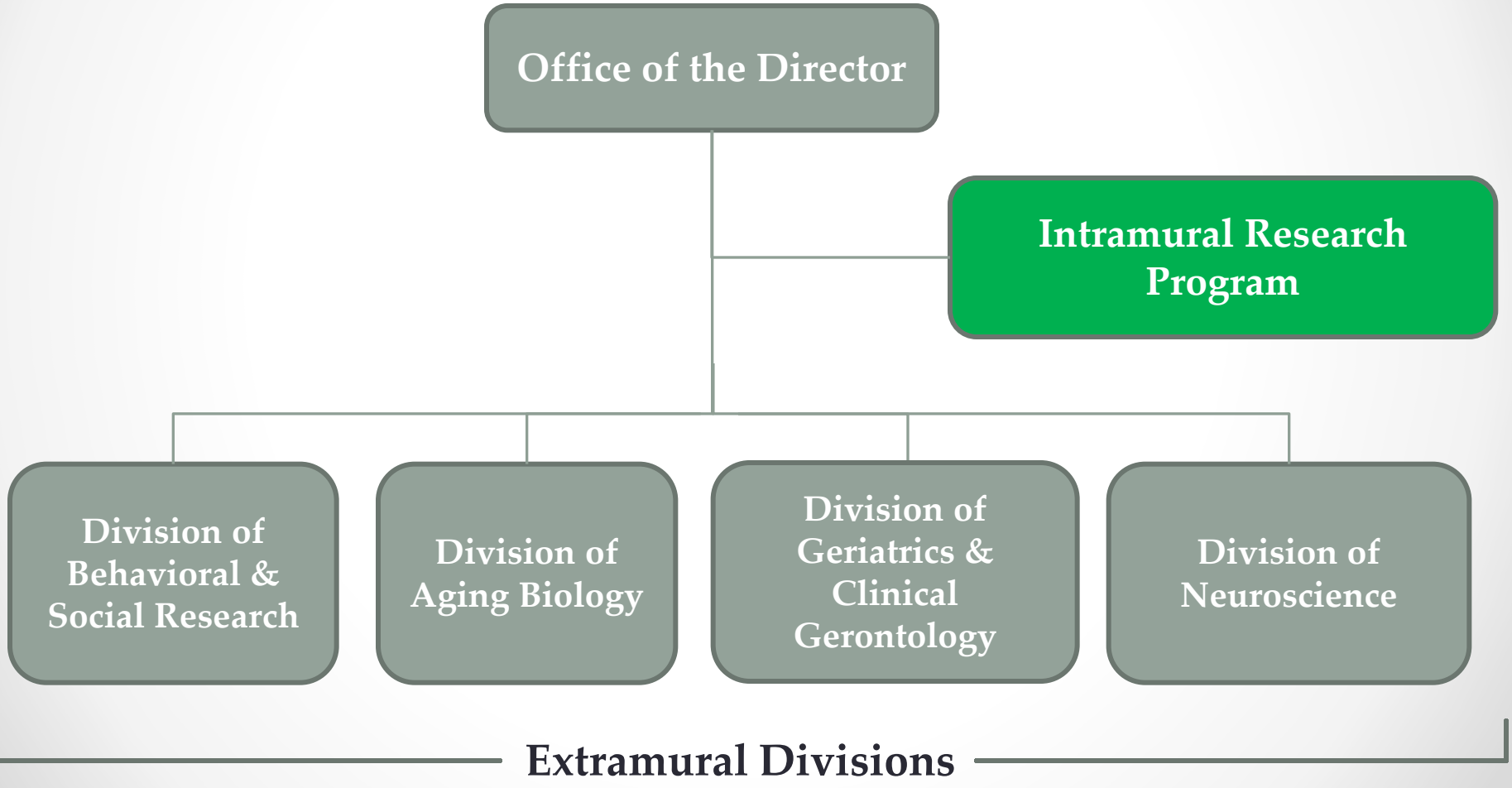
NIA Mission

To improve the health and well-being of older Americans through research, and specifically, to:

- Support and conduct high-quality research on aging processes, age-related diseases, and special problems and needs of the aged
- Train and develop highly skilled research scientists from all population groups
- Develop and maintain state-of-the-art resources to accelerate research progress
- Disseminate information and communicate with the public and interested groups on health and research advances and on new directions for research.

NIA Organization



Relevant funding opportunities

- **"Advancing the Science of Geriatric Palliative Care"**
  - R01: http://grants.nih.gov/grants/guide/pa-files/PA-13-354.html
  - R03: http://grants.nih.gov/grants/guide/PA-files/PA-13-356.html
  - R21: http://grants.nih.gov/grants/guide/PA-files/PA-13-355.html
- **"Pain in Aging"**
  - R01: http://grants.nih.gov/grants/guide/PA-files/PA-13-058.html
  - R03: http://grants.nih.gov/grants/guide/PA-files/PA-13-060.html
  - R21: http://grants.nih.gov/grants/guide/PA-files/PA-13-059.html

Relevant NIA-Supported Research Centers

- **Alzheimer's Disease Research Centers**
  - http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers
- **Claude D. Pepper Older Americans Independence Centers**
  - https://www.peppercenter.org/public/home.cfm
- **Resource Centers for Minority Aging Research**
  - http://www.nia.nih.gov/research/dbsr/resource-centers-minority-aging-research-rcmar

Clinical Course of Advanced Dementia: Complications, Interventions, and Decision-Making

Susan L. Mitchell MD, MPH

Institute for Aging Research
Hebrew SeniorLife

Israel Deaconess Medical Center

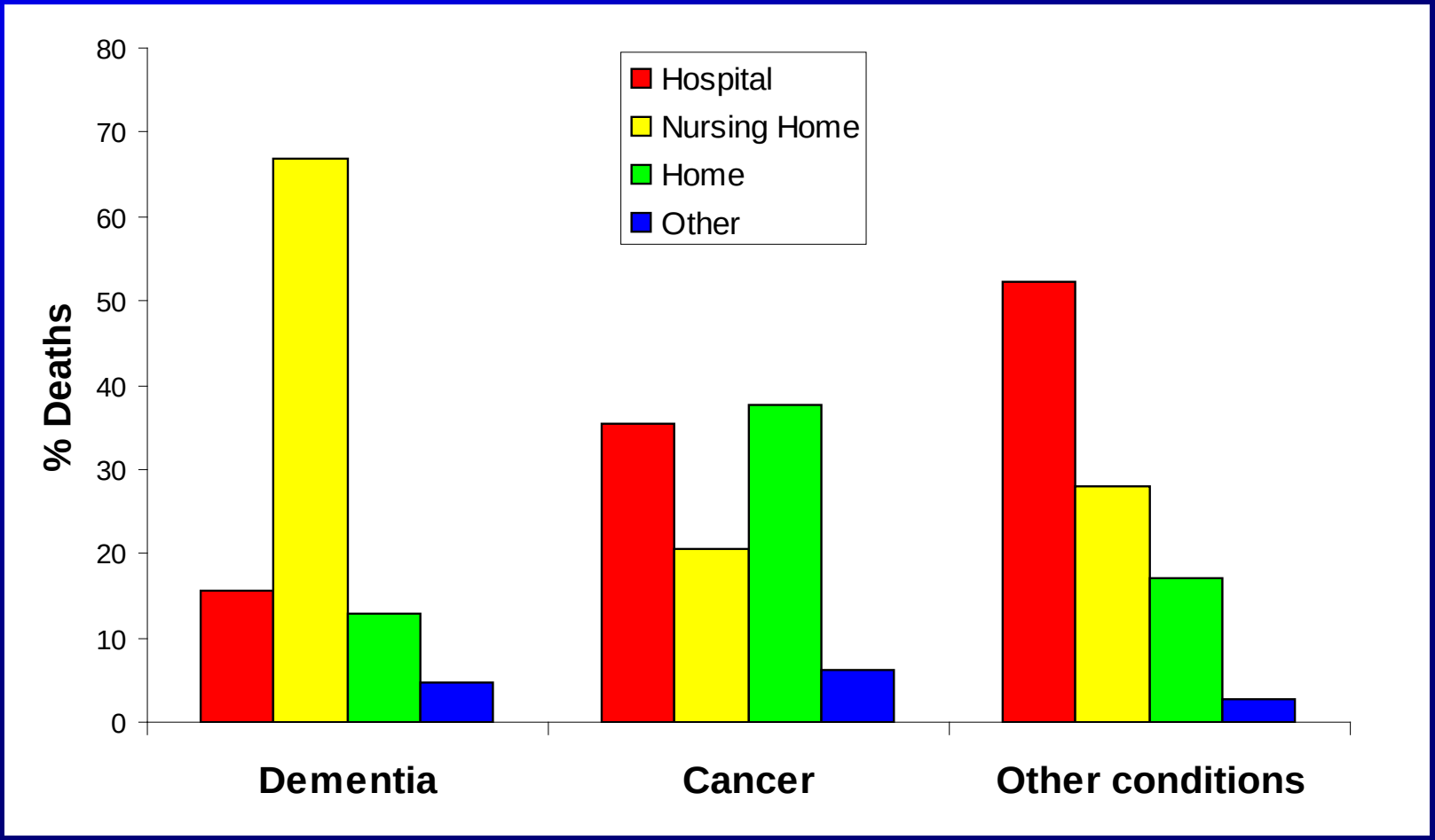
Goals

- Describe clinical course of advanced dementia
- Present most common complications
- Outline an approach to decision-making

Epidemiology

- Over 5 million Americans have Alzheimer's disease, 16 million by 2050.
- 5th leading cause of death in US for persons > 65 years
- Grossly underestimated on death certificates

2001 Location of Death



Mitchell SL et. al. JAGS 2005

Advanced Dementia

Global Deterioration Scale Stage 7

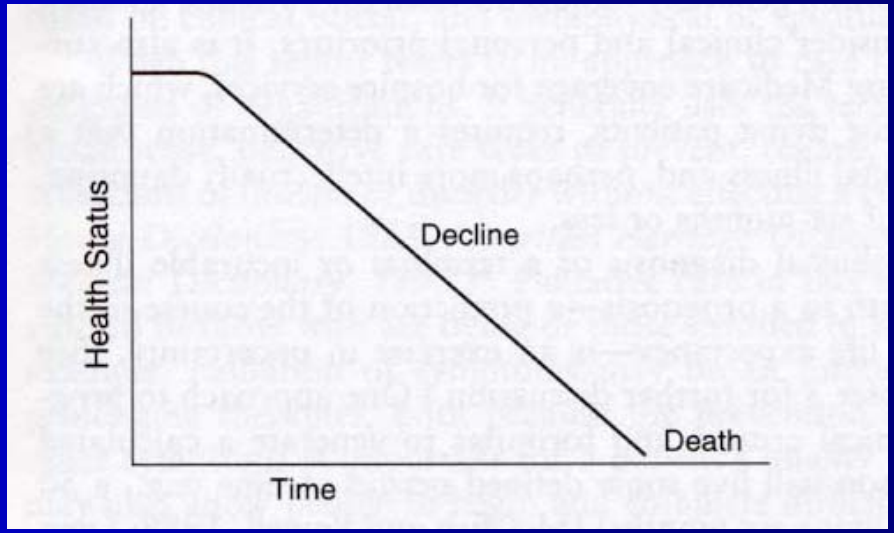
- **Do not recognize family**
- **Loss of all verbal abilities**
- **Non-ambulatory**
- **Incontinent**

** Reisberg B, J Psychiatry 1982*

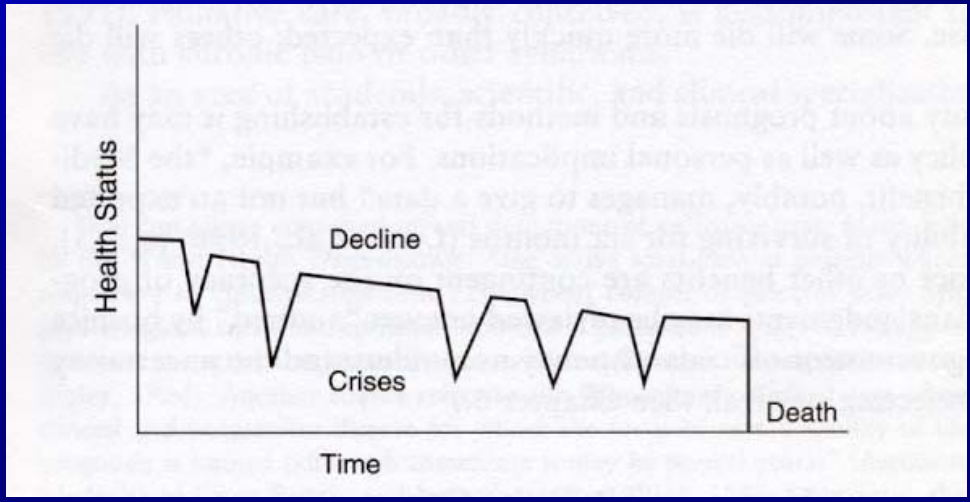
Background

- Palliative care sub-optimal across care settings:
  - Under-recognition as a terminal condition
  - Prognostication
  - Lack of high quality research
  - Under-utilization of hospice

Cancer



CHRONIC DISEASE



Prognosis

- Challenging
- Guides decision making and hospice
- Very limited empiric work
- ADEPT study
  - ADEPT: AUROC = 0.68
  - Hospice: AUROC = 0.55
- Receipt of palliative care should be based on goals of care

* *Mitchell SL, JAMA 2010*

Clinical Course

- CASCADE study
- Prospective study 323 NH resident with advanced dementia
- 22 NHs in Boston

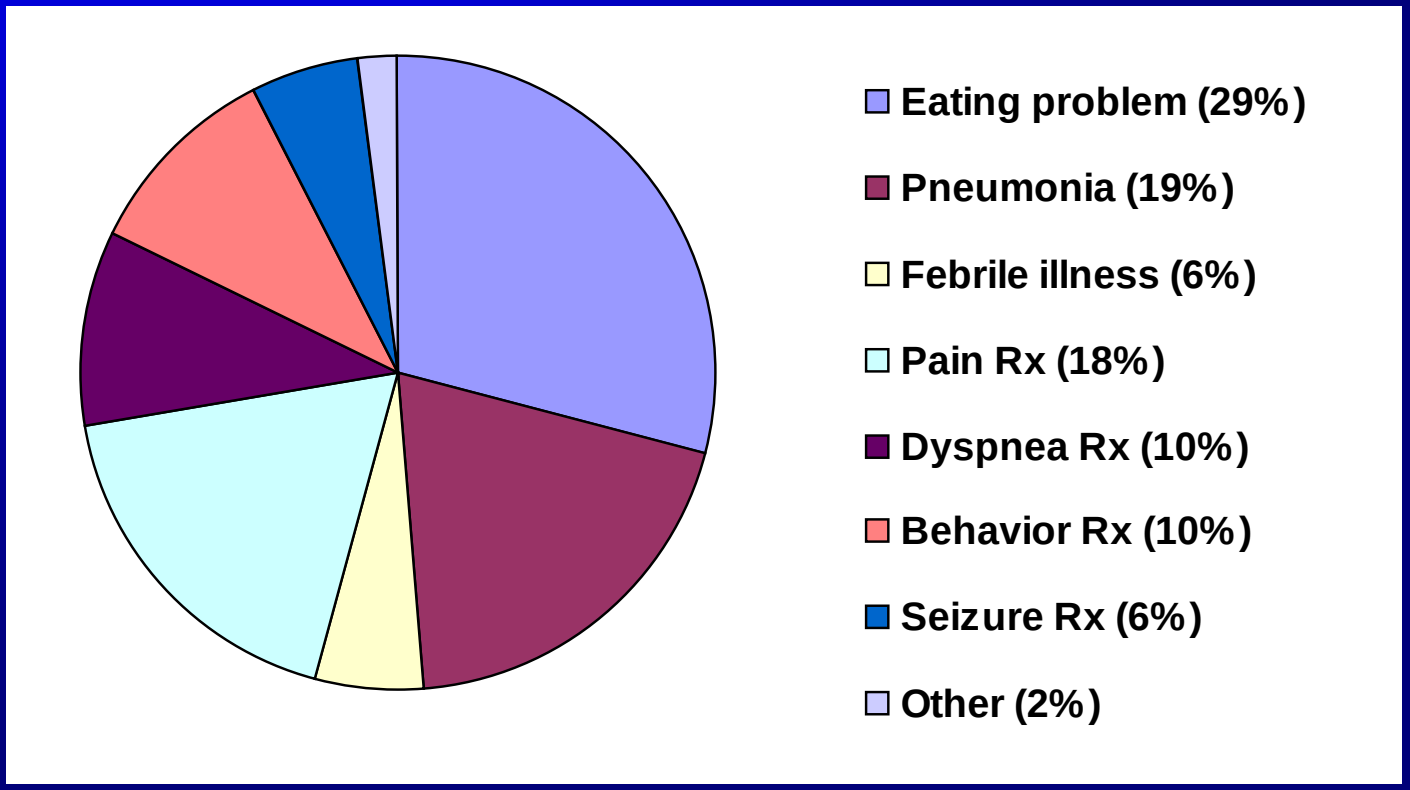
Clinical Course

- **CASCADE study**
  - **Mortality: 55% over 18 months (40% over 12 months)**
  - **Expected complications**
    - **~ 90% eating problems**
    - **~50% recurrent infections/fever**
    - **Others rare (stroke, fracture, MI)**
  - **Burdensome symptoms**
    - **Increase toward death**
    - **Last 3 months: pain 25%; dyspnea 30%**

** Mitchell SL, NEJM 2009*

Decision-Making

Proxy's participated in 126 decisions



Givens JL, JAGS 2009

Decision-Making

- Advance care planning is critical
- Opportunity to discuss early
  - Prepare family for what to expect in advanced stages
  - Elicit wishes
  - Set the stage for future discussions

Ethical Framework

- Beneficence
- Non-maleficence
- Autonomy
- Justice

Steps to Operationalize Ethical Decision-Making

1. Clarify clinical situation
2. Determine primary goal of care
3. Present treatment options
4. Weigh options against perceived values

Step 1: Clarify Clinical Situation

- **Eating problems**
  - **Very common in end-stage**
  - **Last activity of daily living to be lost**

Step 2: Goals of Care

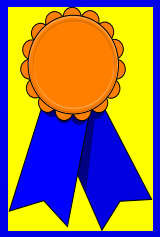
- Life prolongation
- Maintain function
- Comfort

Gillick MR, JAMDA 2001

Step 3: Present Options

- Supportive care vs. long-term tube-feeding (PEG or J-tube)

Ranking the Evidence



- Randomized controlled trial
- None!

- Cohort studies
- Few
- Selection bias

- Case series (many)
- Prognostic information
- No control group

Options: Hand-Feeding

- Provide food and drink to the extent that is enjoyable
- Sub-optimal nutrition in favor of comfort
- Palliative care
  - Treatment not stopped

Tube-feeding

- **Over 30% of nursing home residents with advanced dementia are tube-fed***
- **68% of feeding-tube insertions occur during acute hospitalization****
- **Wide regional variation**

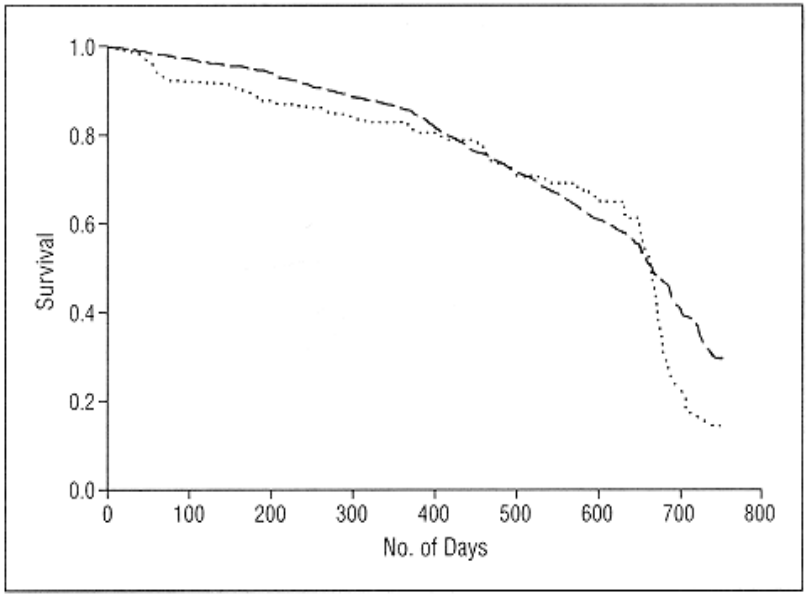
**Mitchell SL et al, JAMA;2004*

***Kuo S et al, JAMDA;2009*

Options: Tube-Feeding

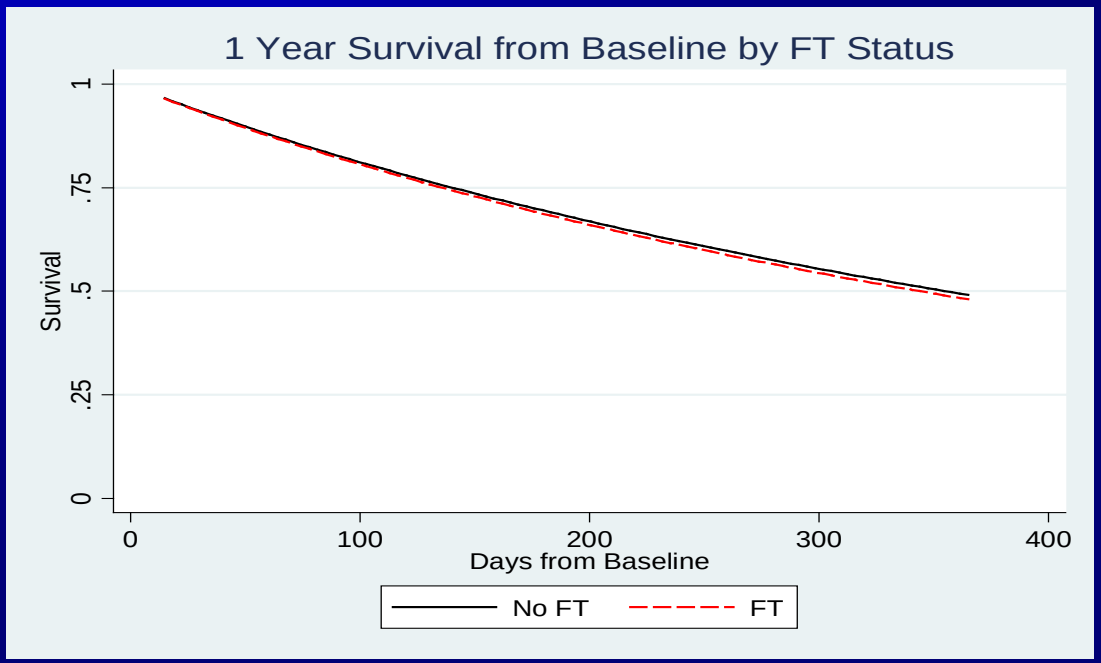
- Purported benefits
  - Aspiration
  - Malnutrition
  - Survival
  - Comfort

Arch Intern Med; 1997



A 24-month survival comparison of residents with severe cognitive impairment with (dotted line) and without (dashed line) feeding tubes.

JAGS; 2012



Tube-Feeding: Risks

- Relatively safe procedure
- Special considerations
  - Agitation
  - Hospital transfer for complications
  - Pressure ulcers: increased risk and poorer healing

Teno et al, Arch Intern Med;2012

Step 4: Weigh Options

Options	Advantages	Disadvantages
Hand-feeding	Tastes food Social Interaction Focus on comfort	Takes Time Inconsistent Intake
Tube-feeding	Nutrition delivered	No Clear Benefits Complications

Step 4: Weigh Options

- Align with goal of care
  - Comfort → Hand-Feeding
  - Prolong life → ???

Step 4: Weigh Options

- **Expert opinion and empiric data**
  - **tube-feeding has no demonstrable benefits in advanced dementia**
  - **tube-feeding should not be offered**

**Gillick MR, NEJM 2000*

#Finucane T et al, JAMA 1999

Pneumonia

Step 1: Clarify Clinical Situation

- Very common in end-stage dementia: ~ 50% last 90 days
- High mortality
- Discomfort:
  - symptoms* and treatment

van der Steen et al, JAGS 2002

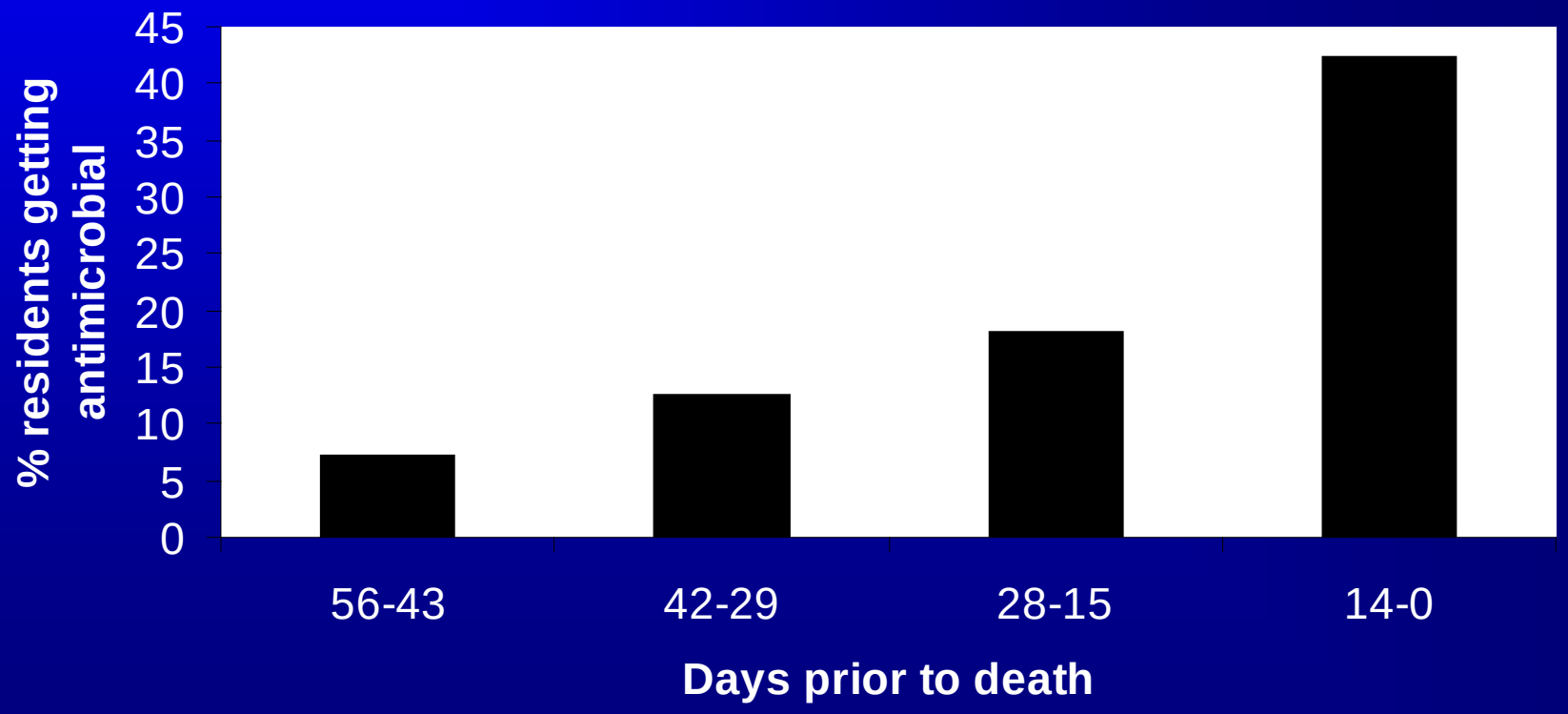
Step 2: Goals of Care

- **Life prolongation**
- **Maintain function**
- **Comfort**

Gillick MR, JAMDA 2001

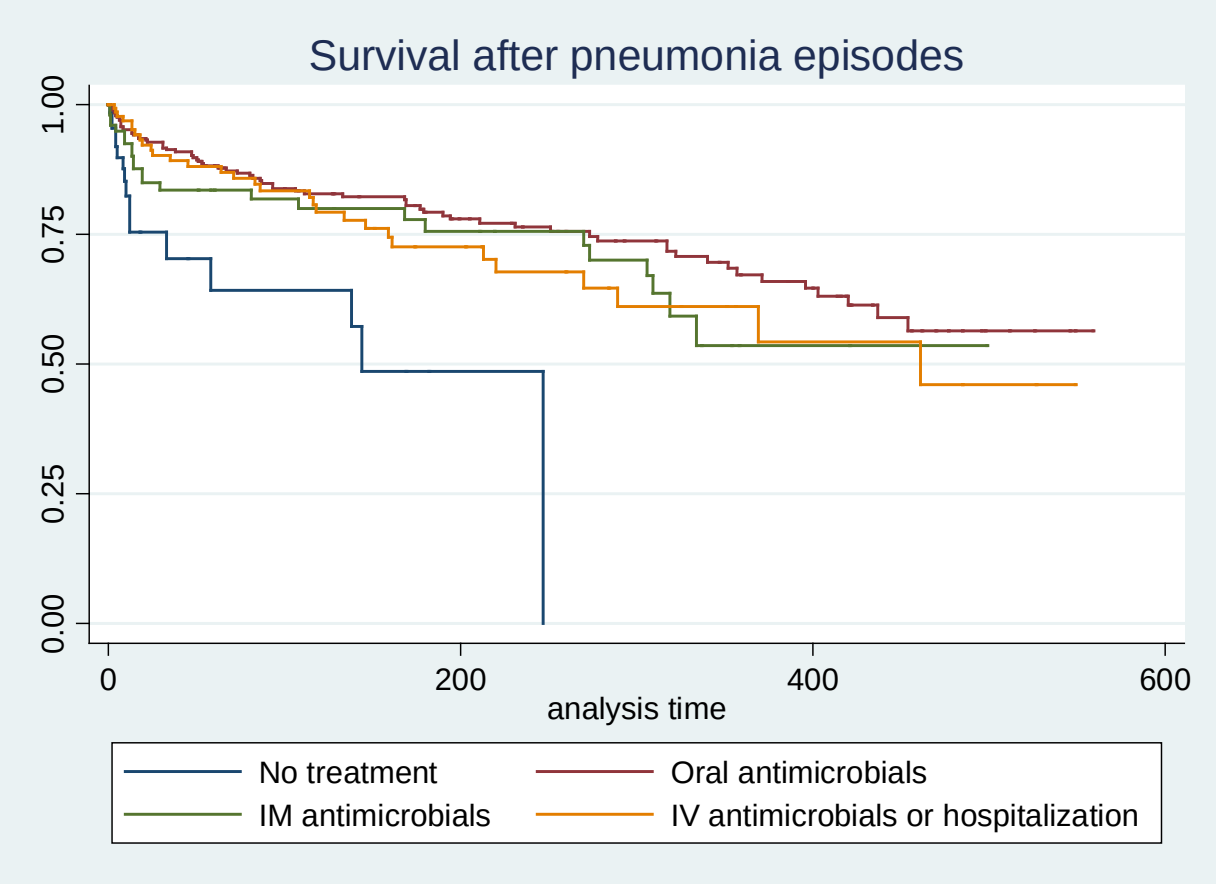
Step 3: Present Options

Antimicrobial Exposure



**D'Agata EMD, Mitchell SL Arch Int Med 2007*

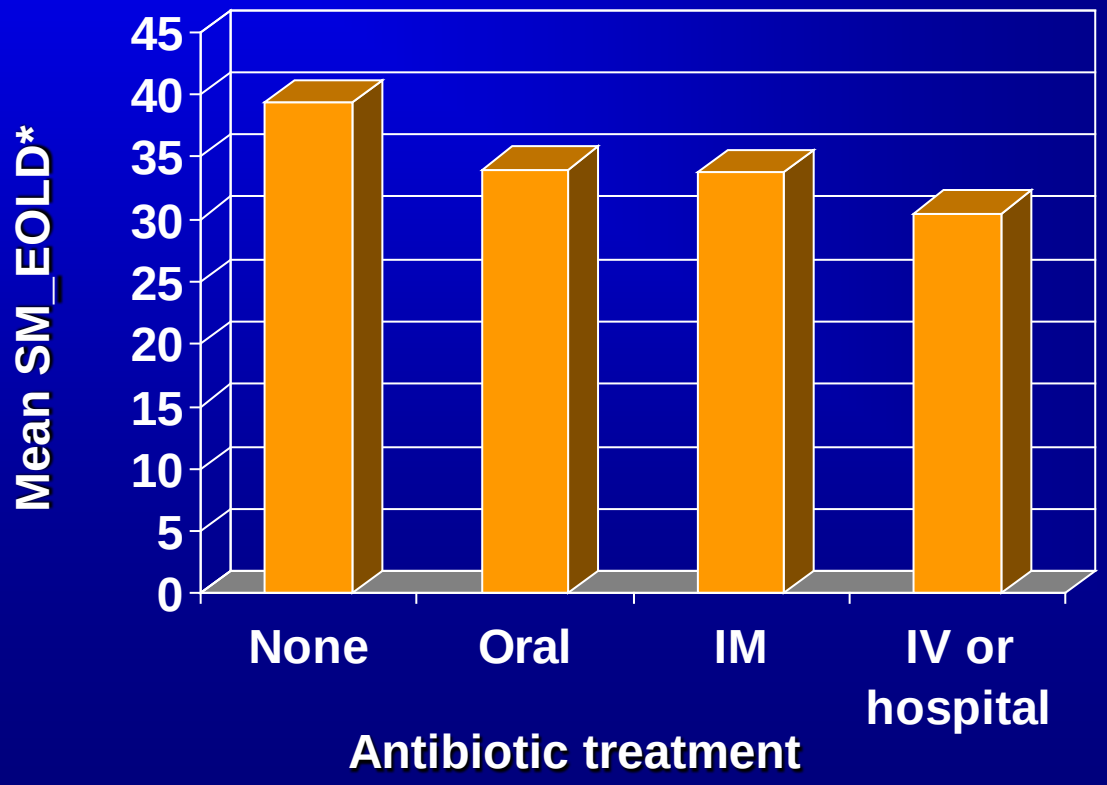
Pneumonia: survival



**Adjusted for age, gender, race, functional status, suspected aspiration, congestive heart failure, hospice referral, do-not-hospitalize order, and chest x-ray having been obtained.*

**Givens JL Arch Int Med 2010*

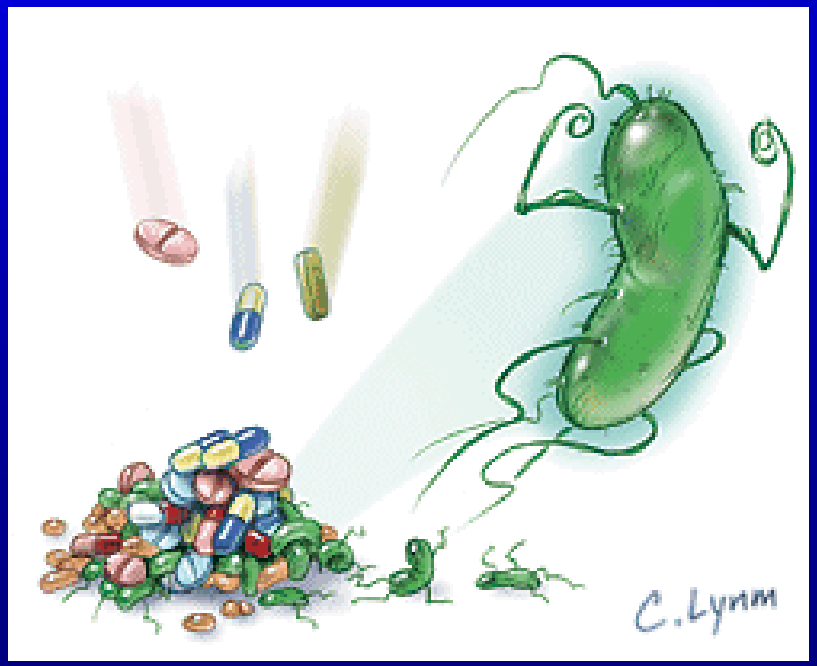
Pneumonia: Comfort



P_{trend}= 0.01

**Symptom Management at the End-of-Life in Dementia, range=0-45, higher score means more comfort*

Antimicrobial Resistance



- Nursing home prevalence study (N=84)
  - 64% advanced dementia colonized
  - 3 times higher than other residents
- Nursing home residents bring resistant bacteria into hospitals
- Public health issue

**Pop-Vicas A, J Am Geriatr Soc 2008*

Step 4: Weigh Options

Options	Advantages	Disadvantages
No antibiotics/ palliation	Greater Comfort	Shorter Survival
Antibiotics	Prolong Survival	Greater Discomfort Cost Antimicrobial Resistance

Step 4: Weigh Options

- **Align with goal of care**
  - **Comfort → Palliation only**
  - **Prolong life → Antibiotics**

    BUT…

    Oral may be adequate

CASCADE: Hospital Transfers

Admissions (N=74)	%
Infections	59
GI Bleed	8
Dyspnea	7
Fracture	5
Heart Failure	3
Dehydration	3
Feeding Tube Cx	3
Other	12

ER Visits (N=60)	%
Feeding Tube Cx	47
Infection	27
Fall	15
Fracture	3
Mental Status Change	2
Chest Pain	2
IV insertion	2
Jaundice	2

Decision to Hospitalize

- What is the goal of care?
  - Survival ⟷ Comfort
  - 95% of proxies state comfort
- Does hospitalization meet that goal?

Outcomes: Patients

- **Most (> 75%) hospital transfers of NH advanced dementia are avoidable…**

Managed same efficacy in nursing home

OR

Not consistent with goal of care/preferences

Summary

- Dementia is terminal illness
- Feeding problems and infections are most common complications and decisions
- Aggressive interventions are less likely when families have a better understanding of prognosis and expected complications

Summary

- Ethical decision-making
  - informed , guided by the goals of care
- Tube-feeding has no demonstrable benefits and should not be offered
- Antimicrobial treatment of pneumonia may prolong life but also cause more discomfort
- Most hospitalizations avoidable

Take home points

- Opportunity for advance care planning
- Focus on goals of care
- Do not feel compelled to offer everything
- Be knowledgeable about the best evidence
- Use decision support tools/geriatric consults/team

Resources

http://www.hebrewseniorlife.org/workfiles/IFAR/Palliative_Care_Dementia_Booklet.pdf

Advanced Dementia and Palliative Care in the Community

Webinar 5

September 24, 2013

Greg A. Sachs, MD

Chief, Division of General Internal Medicine & Geriatrics

Indiana University School of Medicine

Investigator, IU Center for Aging Research &

Regenstrief Institute, Inc.

Disclosure of Potential Conflicts of Interest

- Consultant to CVS Caremark's National Pharmacy & Therapeutics Committee (honorarium)
- Recent grants from AHRQ, CMS, IUPUI, NIH/NIA, Retirement Research Foundation, Walther Cancer Foundation
- Mutual funds; no specific pharma or equipment stocks
- No other grants, consultancies, speaker, etc

Goals for Presentation

- Discuss dementia and palliative care in community setting “upstream” from nursing homes
- Expand on a specific type of advance care planning - POLST
- Address challenges of evaluation and management of pain in dementia
- Discuss hospice and dementia care

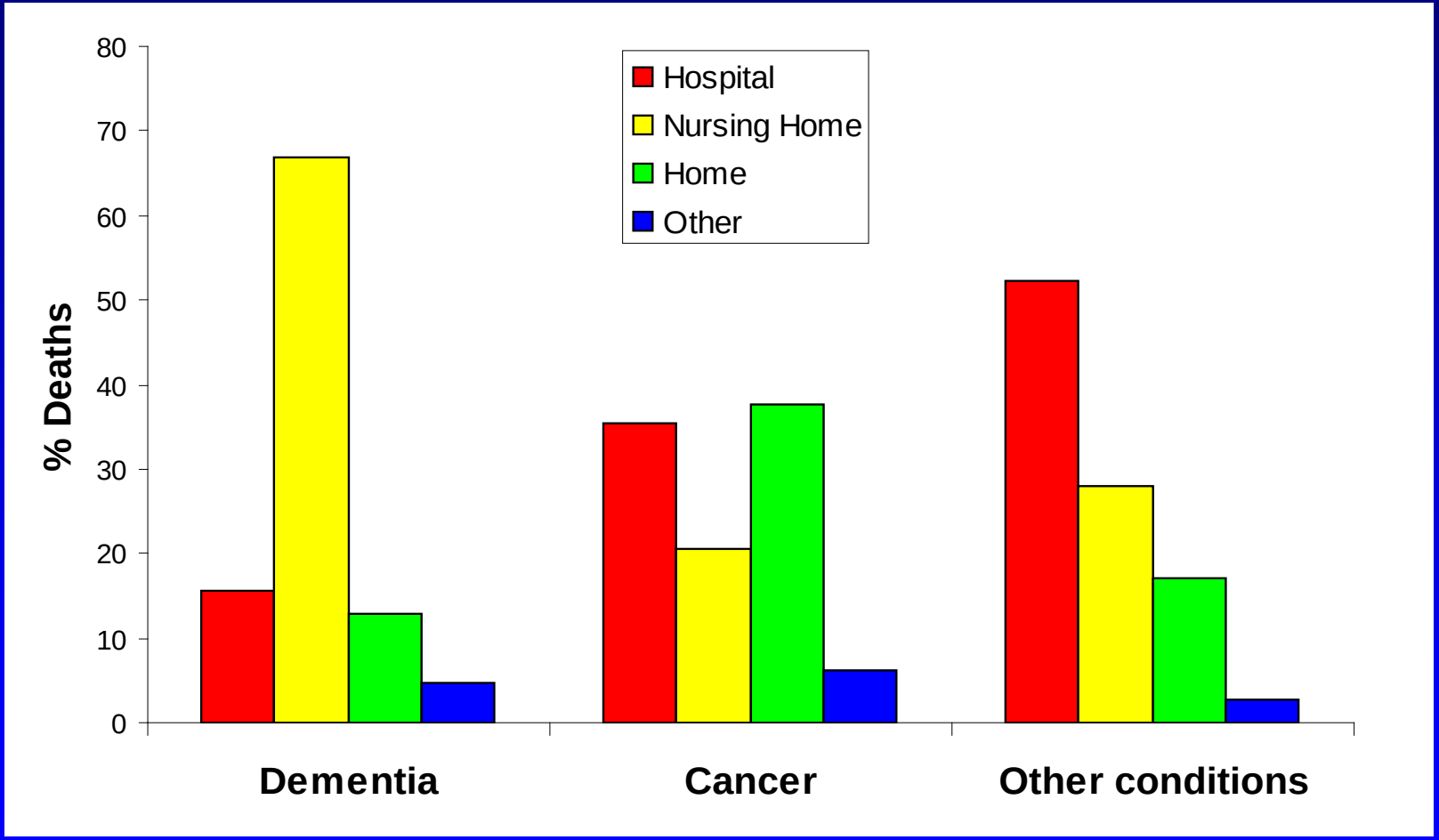
Advanced Dementia

Global Deterioration Scale Stage 7

- Do not recognize family
- Loss of all verbal abilities
- Non-ambulatory
- Incontinent

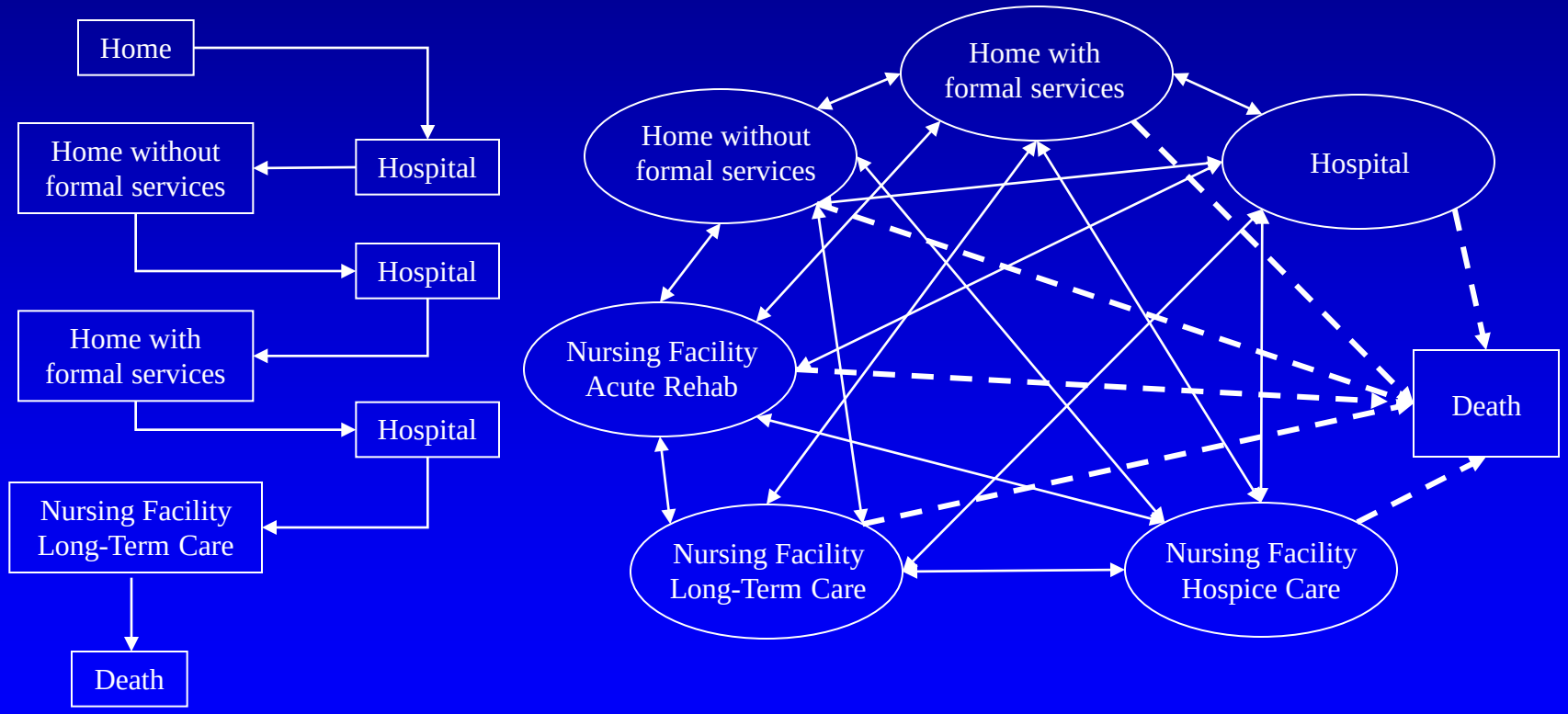
** Reisberg B, J Psychiatry 1982*

2001 Location of Death



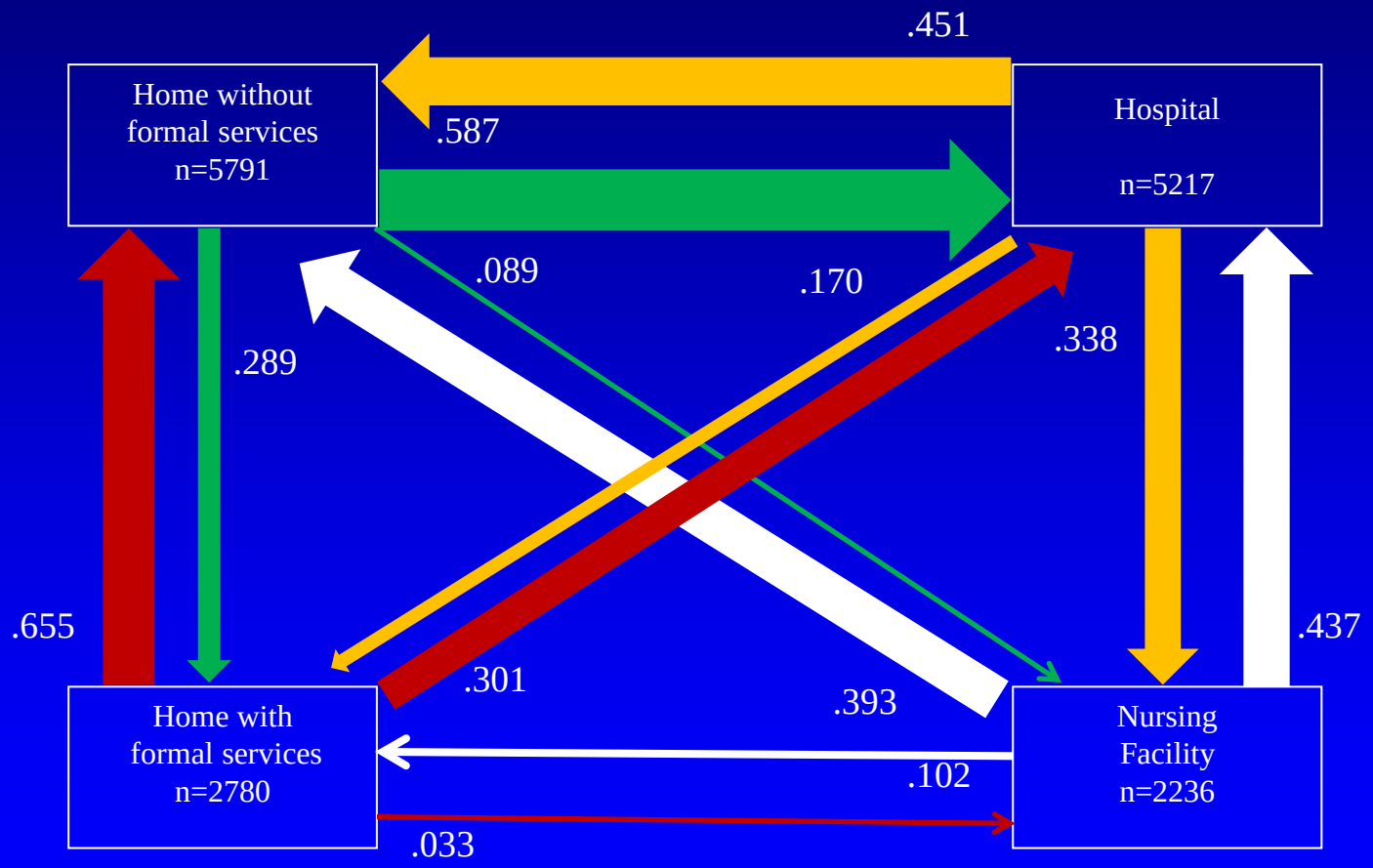
Mitchell SL et. al. JAGS 2005

Progression to Nursing Facility Care and Death is Not Linear for People with Dementia



Callahan et al. JAGS 2012

Outbound Transition Probabilities for Subjects with Dementia



Callahan et al. JAGS 2012

End-of-Life Care and Dementia: Why it's Even Harder

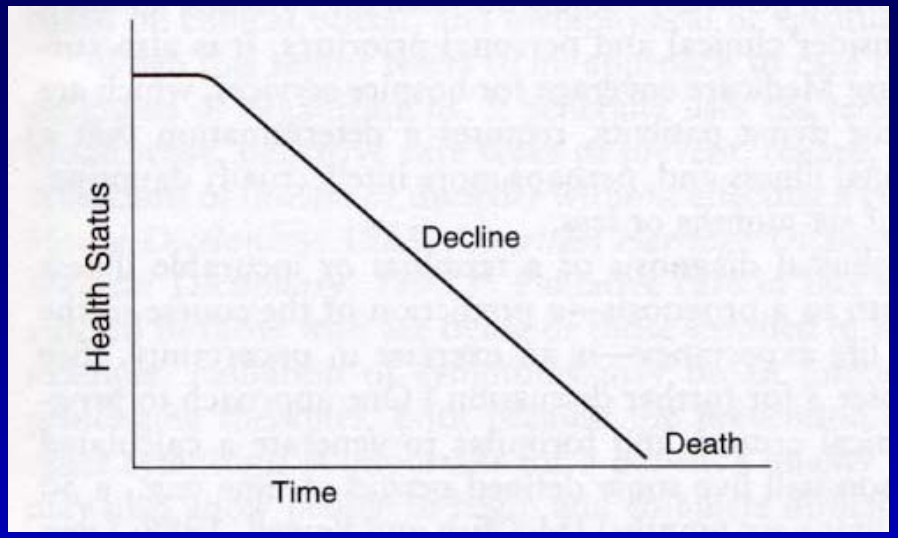
- Conceptual – is dementia a terminal illness?
- Communication, advance directives
- Working with families / proxies
- Prognostic uncertainty

Sachs et al. J Gen Intern Med 2004;19:1057-1063

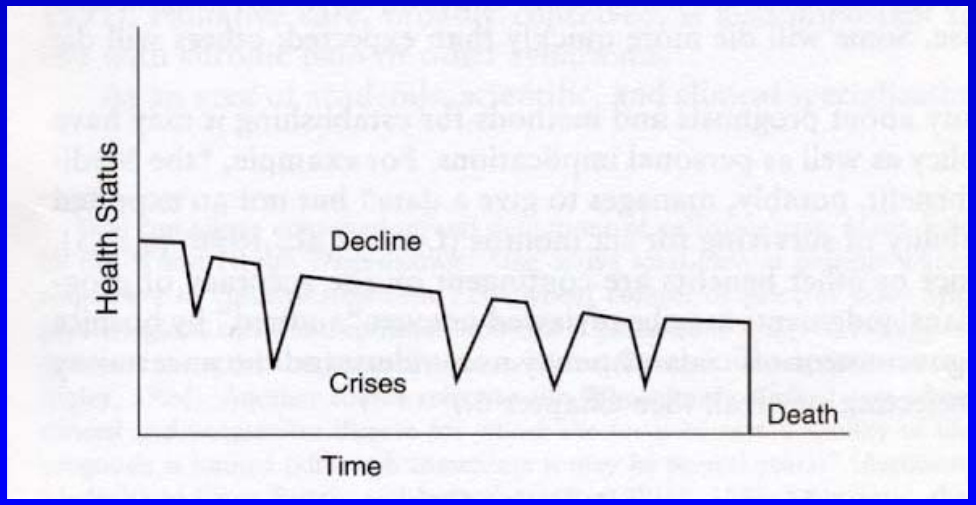
End-of-Life Care and Dementia: More Challenges

- Problems identifying symptoms and titrating therapy
- Difficulty of withholding / withdrawing therapies such as antibiotics, tube feeding
- Institution / system constraints

CANCER



Chronic disease



The POLST Paradigm

- POLST = Physician Orders for Scope of Treatment
  - Converts treatment preferences into immediately actionable medical orders
  - Advanced chronic progressive disease and frailty; terminal illness
  - Preferences to have or decline treatments
  - Transfers across treatment settings with patient
  - Recognizable, standardized form

Consistency of Treatment with Orders for POLST Users

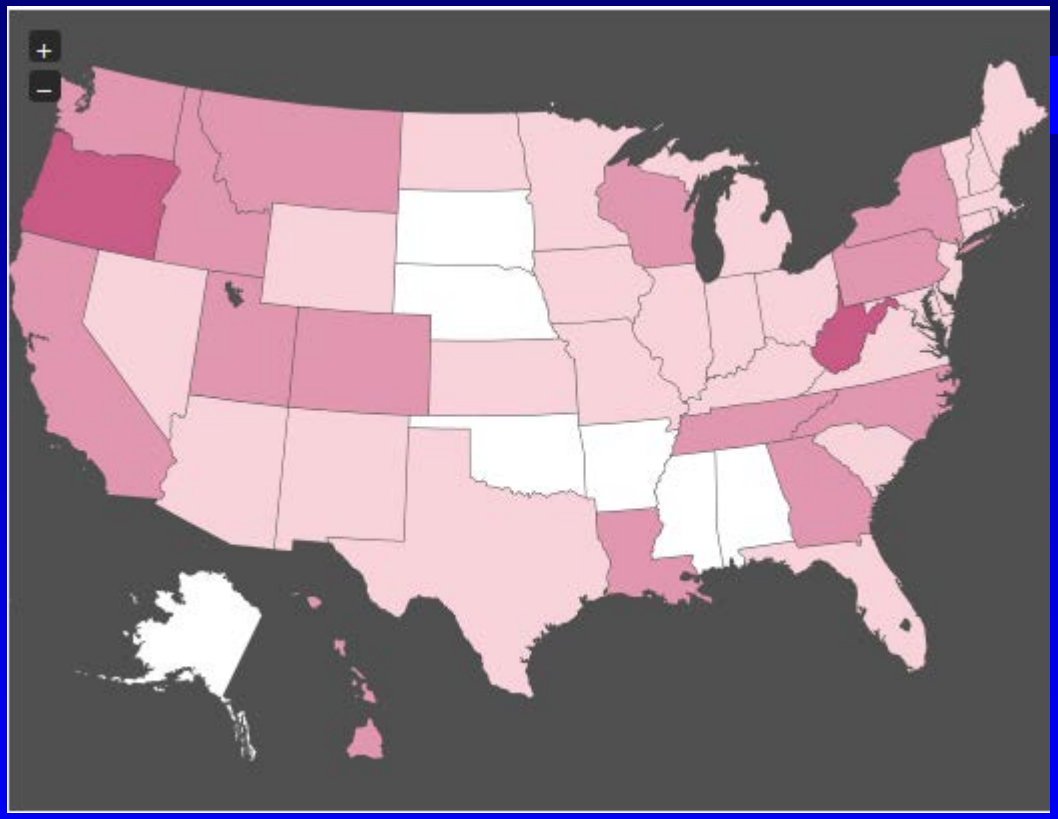
Section	% treatments consistent with POLST Orders
Section A: Resuscitation[a]	98% (300/306)
Section B: Medical Interventions[b]	91.1% (102/112)
Section C: Antibiotics[b]	92.9% (224/241)
Section D: Feeding Tubes[b]	63.6% (14/22)

[a] Reflects consistency of treatments with orders to limit or provide life-sustaining treatments.

[b] Reflects consistency of treatments with orders to limit life-sustaining treatments

Source: Hickman, Nelson, Moss, Tolle, Perrin, & Hammes (2011)

POLST Paradigm Programs



Mature Programs
Endorsed Programs
Developing Programs
No Program

Source: http://www.polst.org/

Pain in Patients With Dementia

- Patients likely to have conditions or be receiving procedures that are painful
- No reliable evidence that pain sensation is diminished in dementia
- Strong evidence that pain is under-recognized and under-treated in older adults, nursing home residents, and patients with dementia

Assessment of Pain

- Verbal report from patient
- Proxy report from family caregiver
- Observation of patient while moving, assessing for nonverbal pain indicators
- Train family caregiver in assessment
- Family caregiver trains us on patient's "pain signature"

http://prc.coh.org/PAIN-NOA.htm

Iowa Pain Thermometer

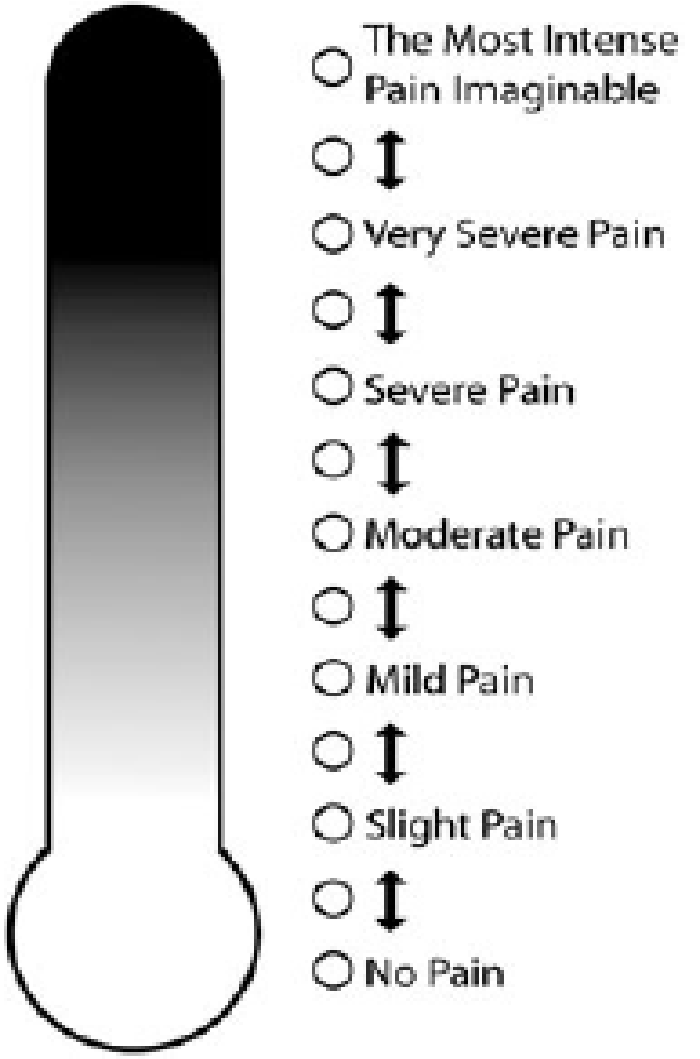


Figure 1 Iowa Pain Thermometer (printed with permission from Keela Herr, The University of Iowa).

Pain in Patients With Dementia

- Weak concordance between patients and caregivers on pain (59% congruence)
- Caregivers' ratings of patients' pain higher than patients' self-report
- Caregivers' more likely to say patient has pain if patient agitated or caregiver depressed (OR 2.77, $p < .03$)

Shega JW et al. J Pain Symptom Manage 2004;28:585-592
Shega JW et al. J Palliat Med 2005;8:567-575

Assessing and Treating Pain

- Even patients with moderate dementia can report pain when asked
- Supplement patient report with that of caregiver plus direct observation (moving)
- Standing doses of analgesics plus breakthrough based on above; not PRN!
- Empirical trials of analgesics for challenging behaviors

Integrating Dementia Care and Palliative Care

- PEACE / IN-PEACE: Integrating dementia/palliative care into ongoing care
  - Advanced care planning
  - Improving symptom management
  - Enhancing caregiver well-being
  - Avoiding burdensome treatments
  - Collaborative care model; supplement to primary care

Shega JW et al. J Palliat Med 2003

Shega JW et al. JPSM 2008

Collaborative Care Model

- Long tradition at IU with IMPACT (depression), GRACE (frailty), PREVENT (dementia), SCAMP (pain and depression), and other studies
- RN, NP, team, or other care coordinators bring specialized care to primary care, home settings
- Proactive assessment and management
- Standardized intervention protocols
- Web-based tracking

PEACE Results: Final 2 Weeks of Life

	PEACE (N = 34)	Non-PEACE (N = 101)	P values
Died at home	65%	54%	P = NS
Died in hospital	27%	30%	P = NS
Died in NH	9%	14%	P = NS
Desired location	79%	65%	P = NS
Pain rating (0-6; sd)	2.20 (1.94)	2.68 (2.18)	P = NS

Results: Final 2 Weeks of Life

	PEACE (N = 34)	Non-PEACE (N = 101)	P values
Hospice			
- Discussed	64%	63%	P = NS
- Enrolled	62%	60%	P = NS
Sensitive	94%	88%	P = NS
Best care possible	94%	84%	P = NS
Expected	76%	54%	P = 0.04
Directives	42%	57%	P = NS

Differences in Care

Table 2
Bivariate Analysis of Differences in Care for Persons with Dementia as Reported by Caregivers for Hospice Enrollees and Nonenrollees, $n = 135$

Variable	Hospice $n = 58$	Non-Hospice $n = 77$	*P*-value
Place of death (%)			
Home	44 (76)	29 (38)	$P < 0.001$
Nursing home	7 (12)	11 (14)	
Hospital	4 (7)	35 (45)	
Other	3 (5)	2 (3)	
Died in location of choice (%)			
Yes	44 (90)	25 (45)	$P < 0.001$
No	5 (10)	30 (55)	
Satisfaction with care (%)			
Excellent	29 (54)	25 (35)	$P < 0.001$
Very good	20 (37)	15 (21)	
Good	3 (5)	18 (25)	
Fair	2 (4)	9 (13)	
Poor	0 (0)	4 (6)	
Mean rating of satisfaction with care[a]	1.59	2.32	$P < 0.001$

Shega JW et al. JPSM 2008

Differences in Care

Table 3

Multivariate Analysis of Differences in Care for Persons with Dementia as Reported by Caregivers: Hospice Enrollee vs. Nonenrollee, $n = 127$

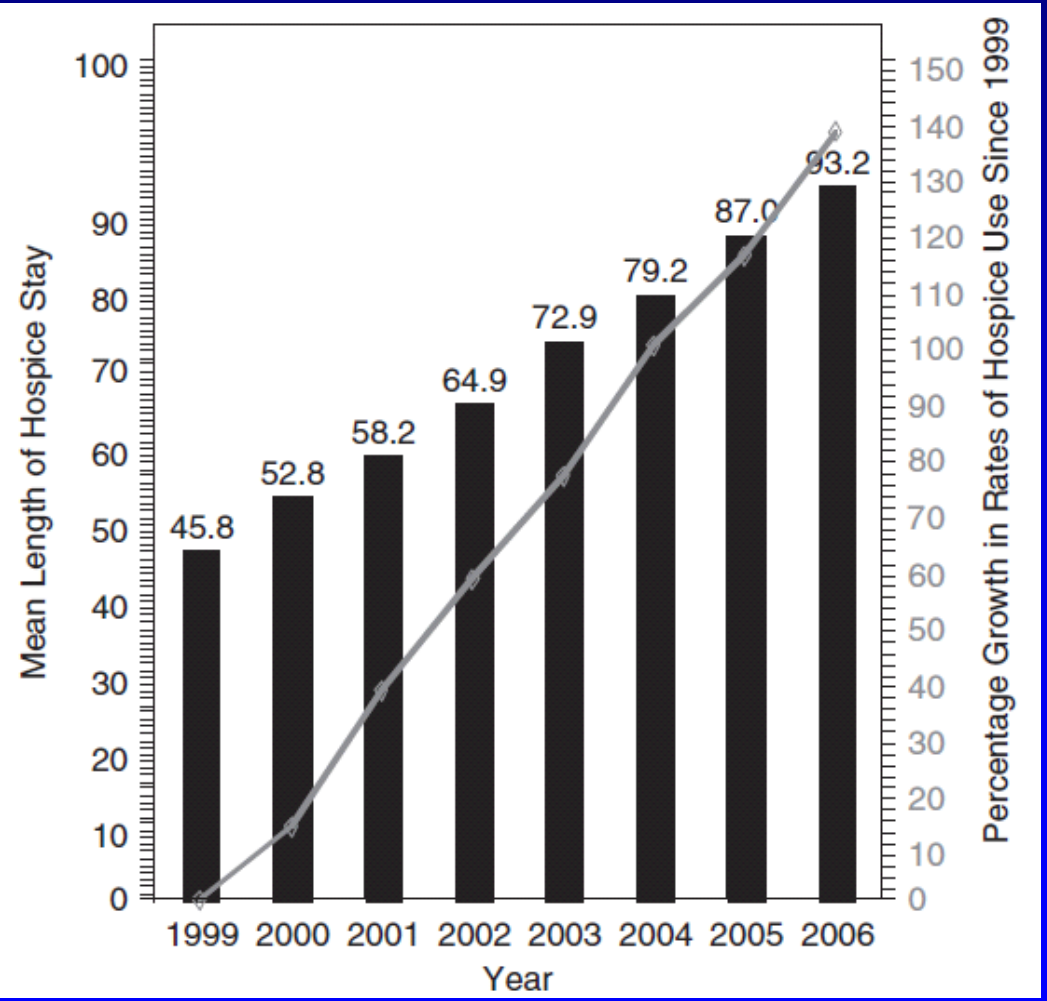
Variable	Adjusted Odds Ratio[a] (95% Confidence Interval)
Died in hospital	0.04 (0.01–0.18)
Died in location of choice	9.67 (2.57–37.0)
Caregiver rated care as excellent or very good	5.65 (2.61–10.34)[b]
Pain at moderate level or higher	0.58 (0.22–1.54)[c]

[a]All models are adjusted for patient age, gender, and ethnicity, and if the caregiver lived with the patient.
[b]Dichotomized from original categorical variables into excellent or very good vs. all others.
[c]Dichotomized from seven-point verbal descriptor pain scale into none through mild vs. moderate and above.

Trends in Nursing Home Hospice

- From 1999 to 2006, the rates of hospice use in nursing homes more than doubled
- Mean lengths of stay also doubled
- Non-cancer diagnoses increased from 69% to 83%

Miller SC et al JAGS 2010



Summary

- Less is known about improving palliative care for people with dementia in the community setting
- Improving care is especially challenging due to conceptual, clinical, system issues.
- Excellent palliative care in dementia is quite attainable: advance care planning, POLST, attentive symptom management, and integration of palliative care into ongoing care are feasible.
- Hospice can play an important role.

Advanced Stage Dementia & Palliative Care: Opportunities for the Aging Network

Greg Link, MA

Aging Services Program Specialist

Administration for Community Living/Administration on Aging

Objectives

- Highlight program-specific opportunities in advance stage dementia & palliative care
- “Touch Points” for promising practices
- Partnerships and collaboration
- Resources

The Aging Services Network

- Administration for Community Living/AoA
- 56 State/Territorial Units on Aging
- Area Agencies on Aging
- Local Service Providers
- Volunteers

The Aging Services Network

- Why the Aging Network?
  - Supports person-centered approaches
  - Supports the continuum of aging
  - Promotes community-based service delivery
- Programmatic Touch Points
  - Planning & program development
  - Service delivery
  - Partnerships

Touch Point: SEP/NWD

- Single Entry Points/No Wrong Door Programs
  - I&R
  - ADRCs
  - Options Counseling
  - Implications for Care Transitions

Touch Point: Supportive Services

- Case Management
- Personal Care, Homemaker, Chore
- Nutrition Programs
  - Congregate
  - Home Delivered

Touch Point: Caregiver Support

- Caregiver Support Programs
  - Caregiver information resources
  - Access assistance – referral
  - Assessment considerations
  - Support group development
  - Education & training opportunities
  - Respite considerations

Touch Point: Legal & Other Services

- Legal Services
  - Advance directives/estate planning
    - Durable Powers of Attorney
    - Living Wills
  - Access to public benefits
    - Income programs
    - Health care financing
  - Private LTC financing options
  - Housing concerns
    - Foreclosure avoidance
    - Public housing programs
  - Elder abuse prevention

Touch Point: LTC Ombudsman

- Ombudsman Programs
  - Resident Support
    - Complaint resolution
    - Care planning
    - Connecting to legal and other services
  - Consultation to facilities
  - State-level Policy Development

Partnering Opportunities

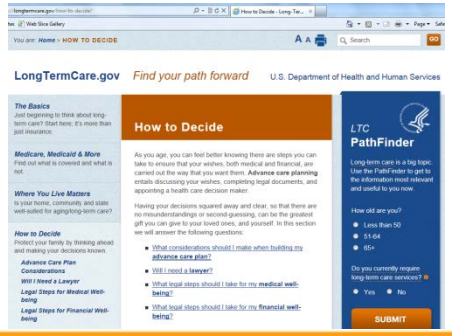
- AAA Advisory Boards/Councils
- Caregiver and respite coalitions
- Alzheimer's Association chapters & other dementia advocacy organizations
- Hospice and palliative care organizations
- ADRC Partnerships
- Medical communities

Resources

- Alzheimers.gov (http://alzheimers.gov/)

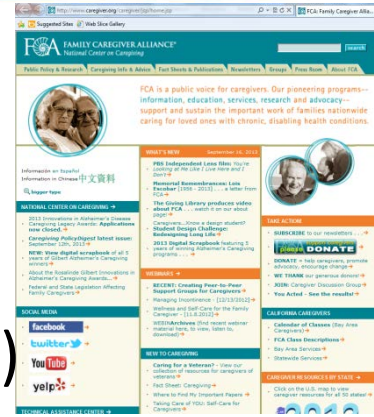
- National Alzheimer's Call Center (http://www.alz.org/)
  1-800-272-3900

- Advance Care Planning: An Introduction for Public Health and Aging Services Professionals (http://www.cdc.gov/aging/advancecareplanning/care-planning-course.htm)



- Long Term Care Clearinghouse (http://longtermcare.gov/how-to-decide/)

Resources

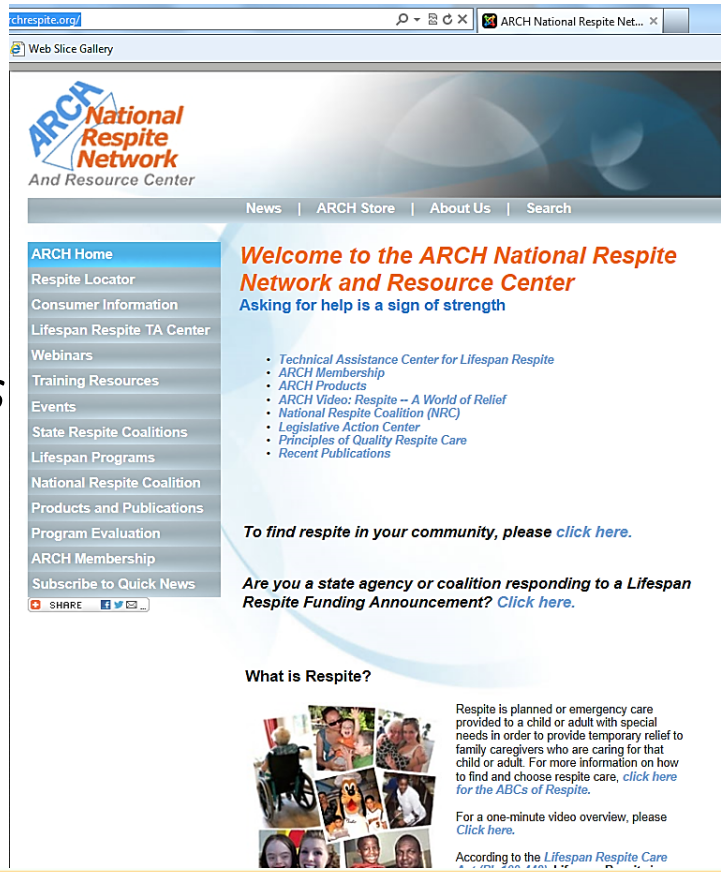


- Family Caregiver Alliance (http://www.caregiver.org/caregiver/jsp/home.jsp)
  - Fact sheets: advanced illness, decision making, grief and loss
  - Family Care Navigator – state-by-state search

- *Place of Death Among Older Americans: Does State Spending on Home and Community-Based Services Promote Home Death?* (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2708119/pdf/nihms-66857.pdf)

Resources

- ARCH National Respite Network - Fact Sheets and National Respite Locator
  - http://archrespite.org/
  - *Families and the Grief Process*
  - *Caregivers and Grief*
  - *Respite for Persons with Alzheimer's Disease*



Questions?

Slides, audio and transcript for 2013 webinar series will be available under Resources and Useful Links at:

http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx