# End of Life Management

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# "We wish we had known about you sooner…"

- Hospice: the well-kept secret
- 25% or more die in first week of service
- Family need for more intensive support

# What is Hospice?

- Interdisciplinary care, usually carried out at the patient's home, with pain management, caregiving, grief management, and bereavement support of family members, for persons with life-ending illnesses.

# What Hospice is Not:

- About Dying (high quality living)
- About Pain (usually not)
- About the patient (only)
- About money
- About a place

# Goals of Hospice Plan of Care

- Self-determined life closure
- Sense of choice and control about what is and isn't happening
- Safe and comfortable dying
- Effective grieving

# Who is eligible for hospice?

- 6 months or less estimated prognosis, as certified by physician

# Prognosis

Point Estimate with Confidence Interval

"I would expect your dad to survive a few months. It is possible that he may survive considerably longer than that; maybe a year or so.

On the other hand, we need to prepare ourselves for the possibility that something precipitous may happen. I would not be surprised if the nurses called me next week to report that he died suddenly. Let's be prepared for, and plan for, any eventuality."

# Plan A and Plan B

Of course we are hoping for the best.

Let’s plan for that.

But let’s also make a plan for what you would want to happen if things don’t go as well as we’d hoped.

# Hospice – when to refer

- Would you be surprised if the patient died in the next 6 months?
- Certification
- Re-certification

# Eligibility Criteria

- Cancer
- Non-Cancer Diagnoses
- Palliative Care
  - XRT
  - Chemotherapy
  - Transfusions

# What to look for:

- Case Examples
  - End Stage Cancer
  - End Stage Dementia
  - End Stage Heart & Lung Diseases

# New Requirements

- Narratives
- Face to Face Visits

# Increased Scrutiny

- Case Examples
  - End Stage Debility
  - End Stage Dementia
  - End Stage Heart & Lung Diseases

# Hospice Services in Seattle

- Several, not for profit
- Hospice of Seattle
- 3 Geographic areas
- 18 patients per team
- 27/16/16 teams
- Team=RN/SW/Vol/CNA/Clergy
- PT/OT/DME available
- Code status / Palliative chemo

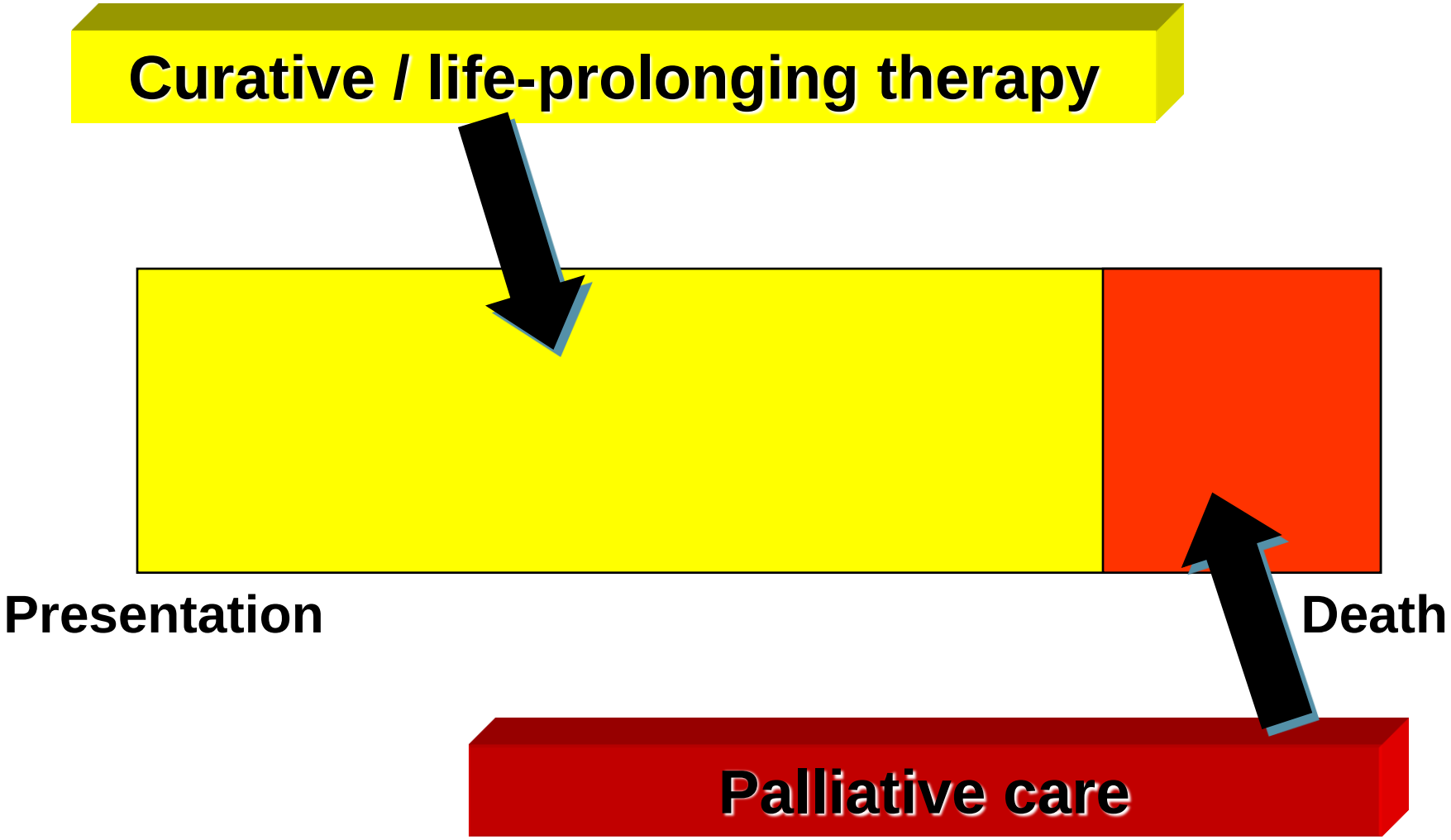
# Team Members & Services

- RN
- SW
- Volunteers
- Nurses Aides
- Chaplain / Clergy

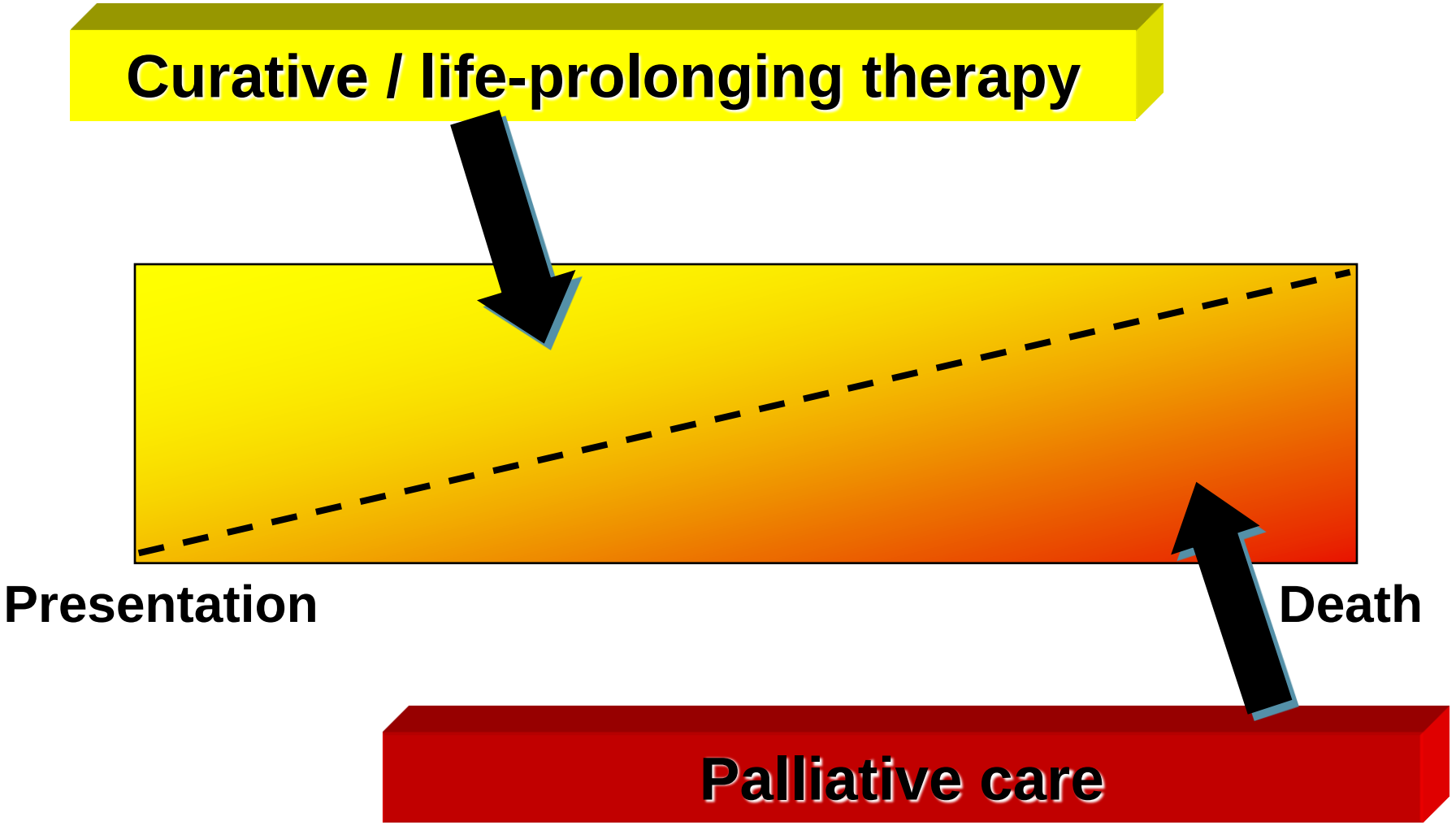
# Role of Primary Physician

- Serve as a co-leader, in collaboration with the medical director of the hospice, in guiding the interdisciplinary team through the course of illness, lending the “physician’s gaze”.

# Dichotomous Care: Curative v. Palliative



# Integrated Therapies: Curative & Palliative



# Duration of Family Conferences and Proportion of Family Speech

| | Mean | SD |
|---|---|---|
| Duration of conference | 32 min | 17-45 min |
| Proportion family speech | 29% | 14-44% |

**McDonagh, Crit Care Med, 2004, 32:1484**

# Proportion Family Speech Correlates with Family Satisfaction

| How well did… | % Family Speech r (p value) | Duration r (p value) |
|---|---|---|
| MD communicate | 0.37 (0.01) | -0.07 (NS) |
| Conf. meet needs | 0.31 (0.04) | 0.08 (NS) |
| How much conflict | -0.31 (0.04) | 0.28 (0.07) |

**McDonagh, Crit Care Med, 2004, 32:1484**

# Palliative Care: Double Effect

- Doctrine of double effect
- Family and all providers need to understand the intention and be comfortable with it.

# Sedative Use in the Last Week of Life

- Doctrine of double effect
- 237 patients on palliative care
- 4 groups – no sedation (123), sedation for 48h (64), sedation for 7 days (16), intermittent (34)
- Survival first 2 groups = 14, and for > 7d group = 36
- Double effect in 2 cases group 2
- Sykes et al Arch IM 163:341-, 2003

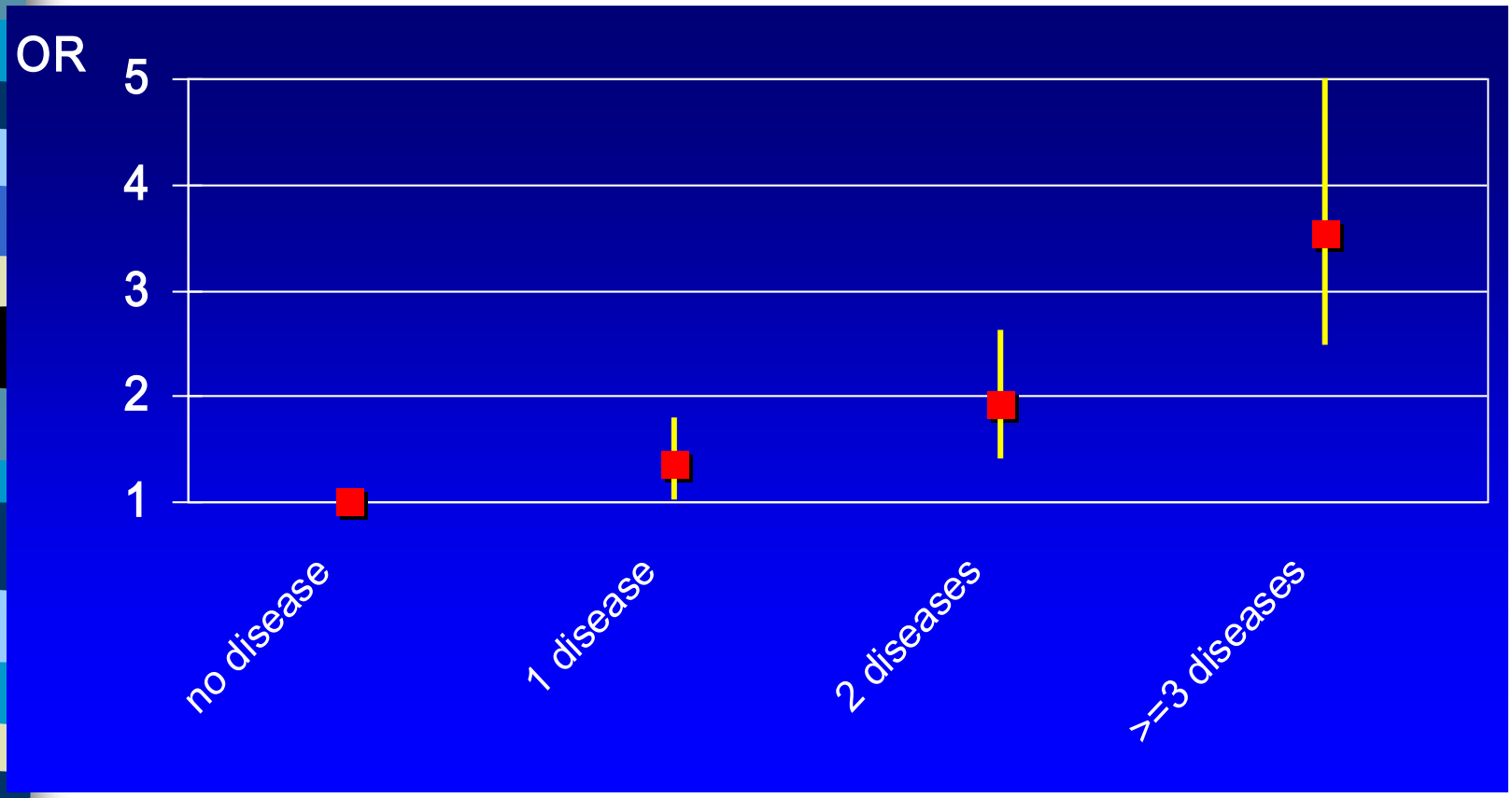
# Concepts of Morbidity

- **Multi-morbidity**: aggregate burden of illness
- **Clusters** of diseases and conditions: their totality of causes and consequences in illness and function

# Definitions

- *Co-morbidity: additional diseases beyond the index disease*
- *Multi-morbidity: co-occurrence of diseases and functional consequences (the whole is worse than sum of the parts)*

# Impact of multimorbidity on 3-year mortality



# Index Diseases vs Multi-morbidity: Hospice "Debility NOS"

- Terminal due to combination of diseases
- Patient / family / MD elect palliative care
- Documented presence of diseases
- Functional decline (Karnovsky)
- ADL dependence (3 or more of 6)
- Impaired nutritional status

# Unique Benefits of Hospice

- Skilled, time-intensive emotional support
- Spiritual support
- 24 hour on-call availability
- Comprehensive grief support service
- Safe Crossings
- Skilled hospice CNA
- Hospice volunteers

# How is hospice paid for?

- Medicare
- Medicaid
- Private Insurance
- Private Payment
- Charity Care

# Challenges in Hospital Setting

- Time!
- The System
- Goals

# Dementia

No evidence that tube feeding in patients with advanced dementia:

- Prolongs survival
- Prevents aspiration pneumonia
- Reduces the risk of pressure sores or infections
- Improves function
- Provides comfort

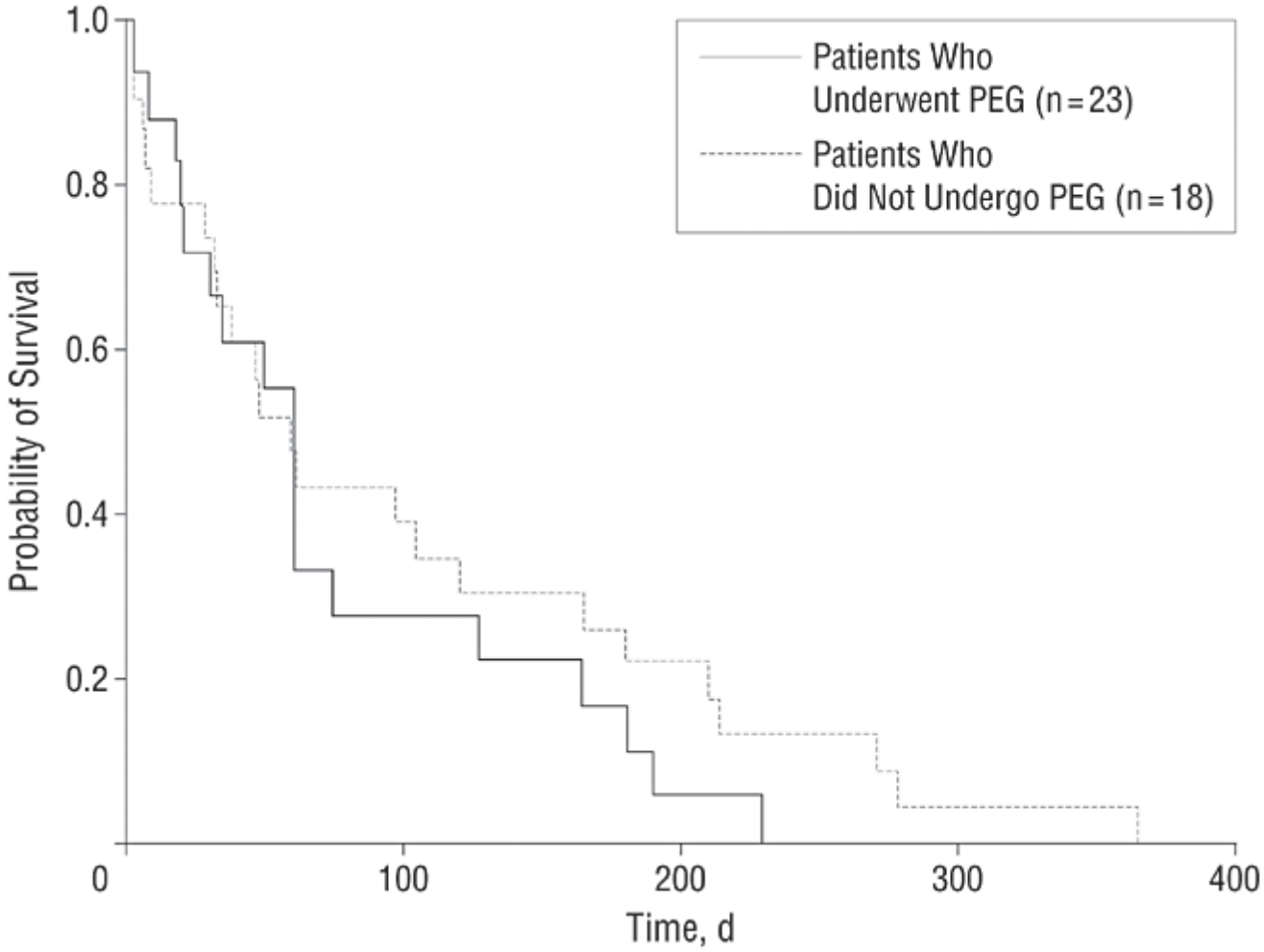
Finucane T, Christmas C, Travis K: Tube feeding in patients with advanced dementia: a review of the evidence. JAMA 1999;282:1365-70

# Dementia

- VA Medical Center, Washington DC
- Of 41 demented patients referred for PEG, 23 received PEG, 18 did not because family declined after discussion of benefits/burdens
- Without PEG placement, median survival was 60 days.
- With PEG placement, median survival was 59 days.

Murphy LM, Lipman TO: Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. Arch Int Med 2003; 163:1351-3.

## Survival of patients with dementia referred for PEG
## VAMC Washington DC




Murphy, L. M. et al. Arch Intern Med 2003;163:1351-1353.



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# Aspiration Pneumonia

- No data show that feeding tubes decrease the risk of aspiration pneumonia.
- Neurogenic dysphagia patients fed with PEG vs. NG had similar rates of aspiration pneumonia.

Park RH et al: Randomised comparison of percutaneous endoscopic gastrostomy and nasogastric tube feeding in patients with persisting neurologic dysphagia. BMJ 1992;304;1406-9.

Fox KA et al: Aspiration pneumonia following surgically placed feeding tubes. Am J Surg 1995;170:564-6.

Finucane TE, Bynum JPW: Use of tube feeding to prevent aspiration pneumonia. Lancet 1996;348:1421-4.

# Other Barriers to Hospice Referrals

- Lack of information
- Cultural tendency toward denial of death
- Patient and family fears

# How to Make a Referral

- Call intake nurse at your hospice of choice
- Liaison
  - Consult
  - Discussion of uncertain cases
- Obtain appropriate paperwork & send

Our goal is to admit the resident to services as soon as desired by the resident/family.

# In Summary…

- Every day counts!
- Informed choices
- Preservation of opportunities
- Life closure
- Increased comfort
- Decreased fear
- Healing and growth
- Emotional support
- Continuing grief support
- Continuum of support
- Healing and meaning-making at EOL