

You Rarely Get What You Don't Know You Want

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The Nature of Suffering and the Goals of Medicine

- “The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick.”
- “Failure to understand the nature of suffering can result in medical intervention that, though technically adequate, not only fails to relieve suffering but becomes a source of suffering itself.”

Eric Cassell, *NEJM*, 1982;306:639-45

Variation in Care at the End of Life

- Variation is the only constant
- Not based on patient preferences
 - Which go largely unknown
 - But should and could be, if known

Impact of Discussions About End-of-Life Care

- Surveyed 332 patients with advanced cancer at 4 centers
- “Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?”
- 123 out of 332 (37%) had discussions with their physicians
- Patients not depressed, sad, or worried
- No patient characteristics predicted having a discussion

Wright AA et al. *JAMA* 2008;300:1665-73

Discussions About End-of-Life Care Are Good for Patients and Families

- End-of-life discussions are associated with:
 - Better quality of life near death
 - Fewer invasive interventions
 - Better outcomes for caregivers

Wright AA et al. *JAMA* 2008;300:1665-73

Variation in Care at the End of Life

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- Not based on patient preferences
- Culture rules
 - We are the culture, and we can change it

Awareness of End-of-Life Terms

California, 2011

PERCENT SAYING THEY HAVE HEARD OF THESE TERMS

Hospice care

73%

Do-not-resuscitate (DNR) order

63%

Advance directive

38%

Palliative care

17%

POLST

13%

Final Chapter: Californians' Attitudes and Experiences with Death and Dying
www.chcf.org/publications/2012/02/final-chapter-death-dying

Variation in Care at the End of Life

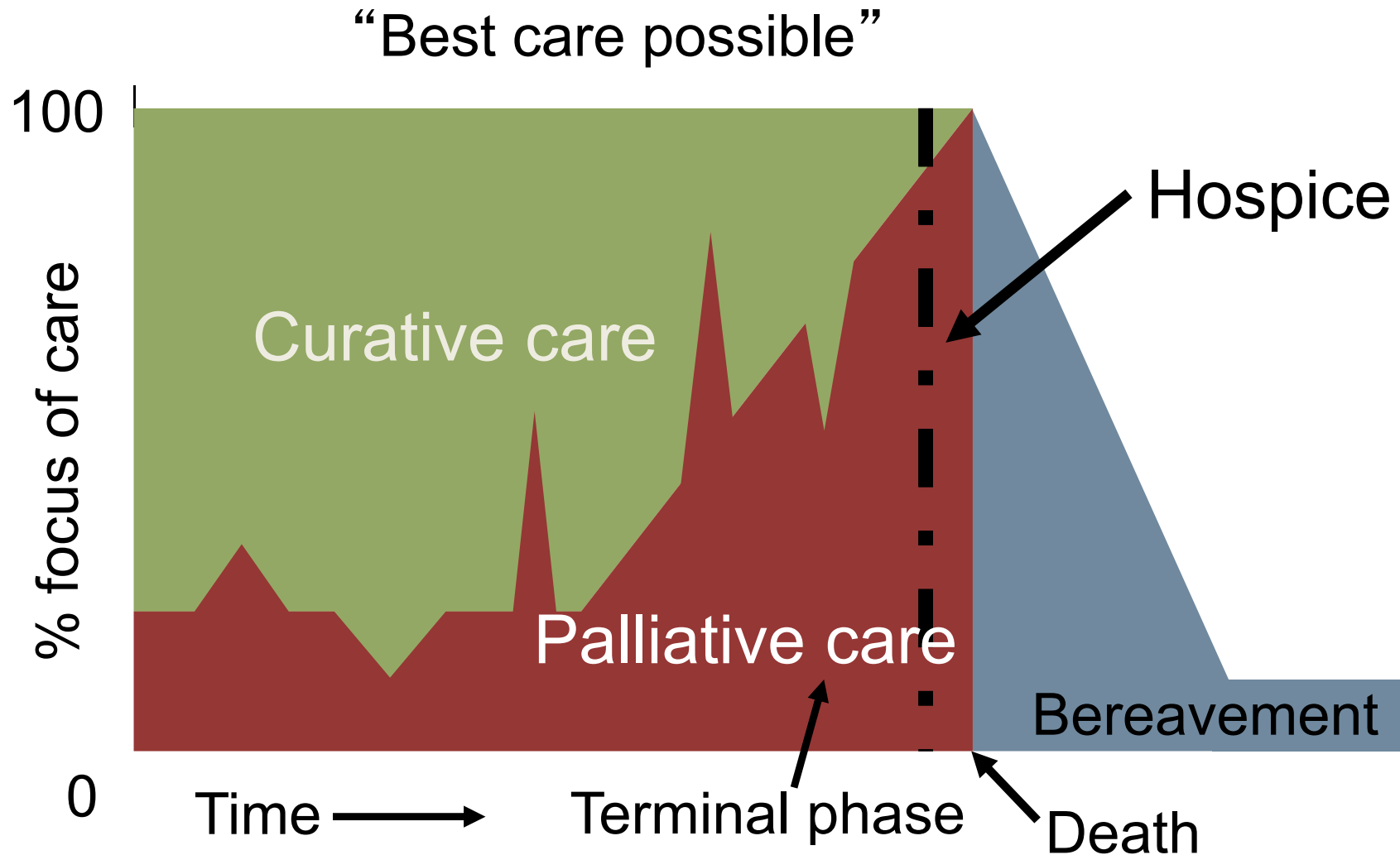
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- Patients:
 - Don't know what to ask for or what is possible

Palliative Care

- Palliative care is specialized medical care for people with **serious illnesses**. This type of care is focused on providing patients with **relief from the symptoms, pain, and stress of a serious illness** – whatever the diagnosis.
- The goal is to **improve quality of life** for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an **extra layer of support**. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Center to Advance Palliative Care 2011

Concurrent Model of Palliative Care



Palliative Care Improves Outcomes

- Better quality of life
- Improved symptoms
- Less depression
- Less likely to receive aggressive care at end of life
- Longer life (11.6 vs 8.9 months)
- Higher satisfaction
- Better outcomes for loved ones
- Cost savings

Morrison et al, *Arch Int Med* 2008;168:1783-90

Gade et al, *J Palliat Med* 2008;11:180-90

Temel et al, *NEJM* 2010;363:733-42

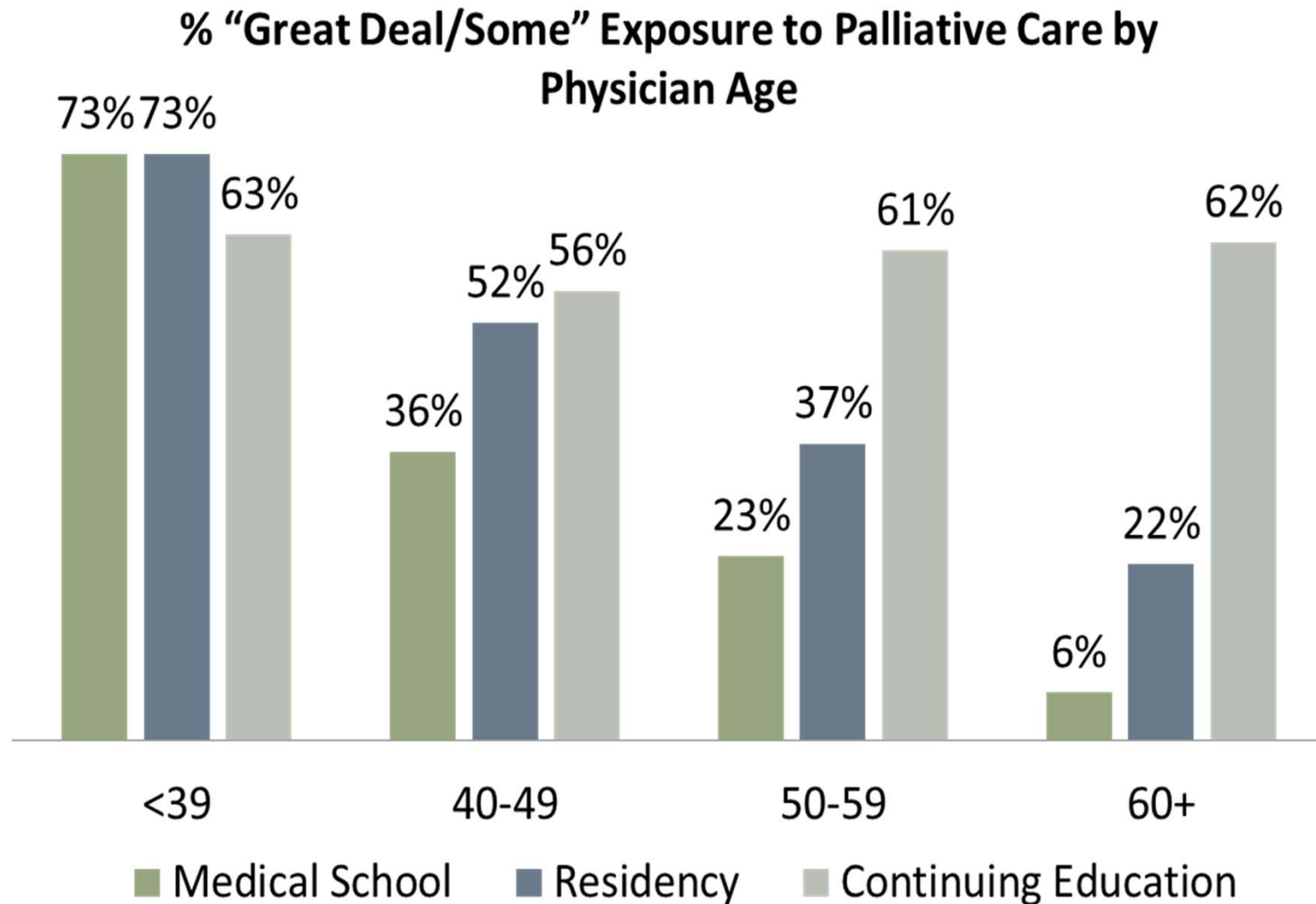
Discussions About Living...not Dying

- Preferences, values, goals
 - When you look to the future, what do you hope for?
 - When you think of what lies ahead, what worries you the most?
- Choices
 - What else is available?
- Sharing
 - With loved ones, providers
 - Written and available

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- Providers:
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Increasing Physician Familiarity



n=500 board-certified US physicians from AMA master file; 2011

RF/NJ Poll



"There's no easy way I can tell you this, so I'm sending you to someone who can."

Better Words to Say



“Would you like us to do everything possible?”

- “How were you hoping we could help?”

Pantilat, *JAMA* 2009;301:1279-81

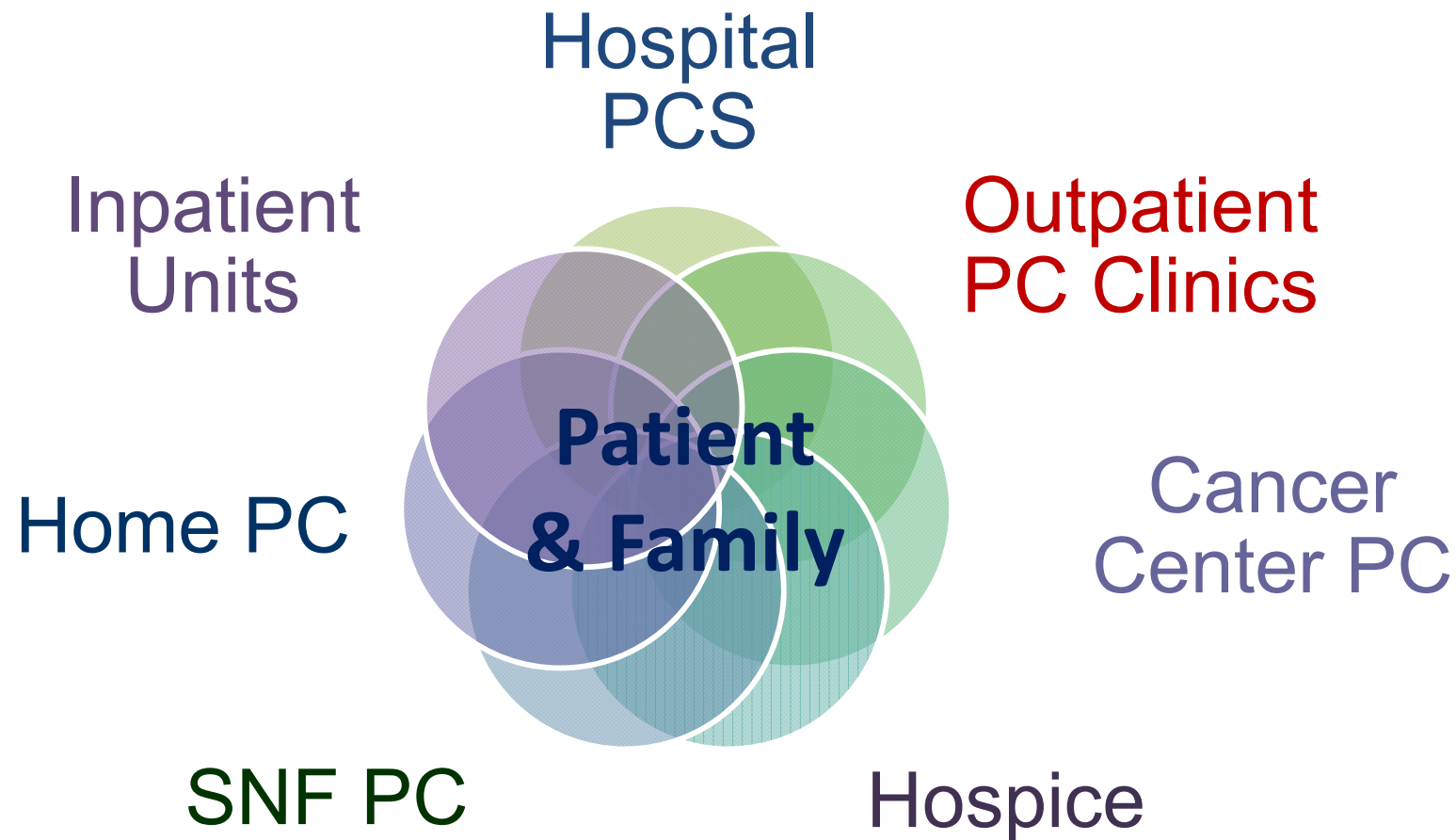
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- Providers:
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- Services are lacking

Availability of Palliative Care Services

- Hospitals: Fewer than half offer palliative care
- Outpatient palliative care services
 - Only 8% of hospitals offer them
- Hospice: Every community in California
 - Enrollment limited by 6-month prognosis and need to give up disease-focused care
- Home-based palliative care: Rare
- Palliative care-certified physicians
 - 327 in California: Fewer than one per hospital

Continuity: Building the Safety Net of Palliative Care



Recommendations

- Mandate palliative care services in hospitals
- Expand hospice benefit for concurrent care
- Integrate palliative care into bundled services for people with serious illness such as dementia, heart failure, cancer
- Require outpatient, home, and nursing home palliative care services in all benefit plans
- Support training of palliative care physicians and nurses
- Embark on public information campaign about palliative care

Optimism

- “Although the world is full of suffering, it is also full of the overcoming of it.”
-- Helen Keller, Optimism, 1903

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