National Cancer Institute

BEHAVIORAL RESEARCH

CANCER CONTROL AND POPULATION SCIENCES

The presentation will begin shortly

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Decision-Making Steering Committee Speaker Series

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National Institutes of Health

Shifting gears: the transition from curative to palliative treatment goals

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Objectives

- Describe the major challenges of making the transition from curative to palliative care goals in cancer treatment
- Explore future research needs

Case 1

- J.B.: 68-year-old man with advanced bile duct carcinoma
  - s/p multiple cycles chemotherapy past 6 months
  - Progressive disease, decline in fx status
  - Multiple hospitalizations in prior 3 months: cellulitis, urinary tract infection, dehydration, intractable pain
  - Progressive jaundice, ascites, peripheral edema.
- Primary oncologist decided against further chemotherapy
  - Hospital chart note: "Nothing more for me to do"
- Requested Palliative Care Service consultation
  - Discuss goals of care, assume primary responsibility for all further medical care, initiate hospice care

Case 1

- Initial discussion with J.B. and family
  - Unaware, surprised, disappointed that chemotherapy would not be continued
  - Reluctant to pursue palliative vs. curative goals, refused hospice care
- Subsequent interactions over next 3 days
  - Gained trust, elicited goals, discussed prognosis
  - Agreed to hospice care, discharged home
- Discharged from hospital 4 days later
  - Palliative Care attending = primary physician
  - Died 7 weeks later in home hospice program

Case 2

- D.E., a 64 y.o. female with metastatic breast CA dx'd 2 y. ago
  - S/P high dose chemo + BMT
  - Disease recurrence 6 months ago, treated with chemotherapy, radiation therapy
  - New onset of cortical blindness 1 month ago, new diagnosis of leptomeningeal carcinomatosis
  - Whole brain irradiation 1 month ago
- Now admitted with increasing confusion, lethargy, anorexia, dehydration, failure to thrive
  - Physical examination: severe cachexia, dehydration, lethargy, generalized weakness, blindness
  - Laboratory indices: dehydration, electrolyte abnormalities, hypoalbuminemia, anemia

Case 2

- Initial supportive treatment
  - Intravenous hydration, correction of electrolyte abnormalities
  - Nasoenteric tube feeding
  - Pain and symptom control
- Oncology consultation: recommended intrathecal chemotherapy, although small chance of benefit
- Patient and family undecided
  - Questioned the benefit, expressed concern about poor performance status
- Internist requested Palliative Care Service consultation

Case 2

- Palliative care team held meeting with patient, family, internist, oncologist
- Decision for further chemotherapy postponed
- Patient discharged home with nasoenteric tube feeds, VNA support
- Patient's functional status continued to decline over next 2 weeks
- Further discussion with patient and oncologist: patient refused chemotherapy
  - Nasoenteric tube discontinued
  - Home hospice care initiated
- Patient died 3 weeks later at home

Shifting gears

- Transition from curative to palliative treatment goals
  - Fighting disease vs. living with disease
  - Prolonging life vs. relieving suffering
- Exceedingly difficult: maybe the hardest endeavor in health care
  - For patients/families
  - For physicians
- Why is it so difficult?

Shifting gears: barriers and solutions

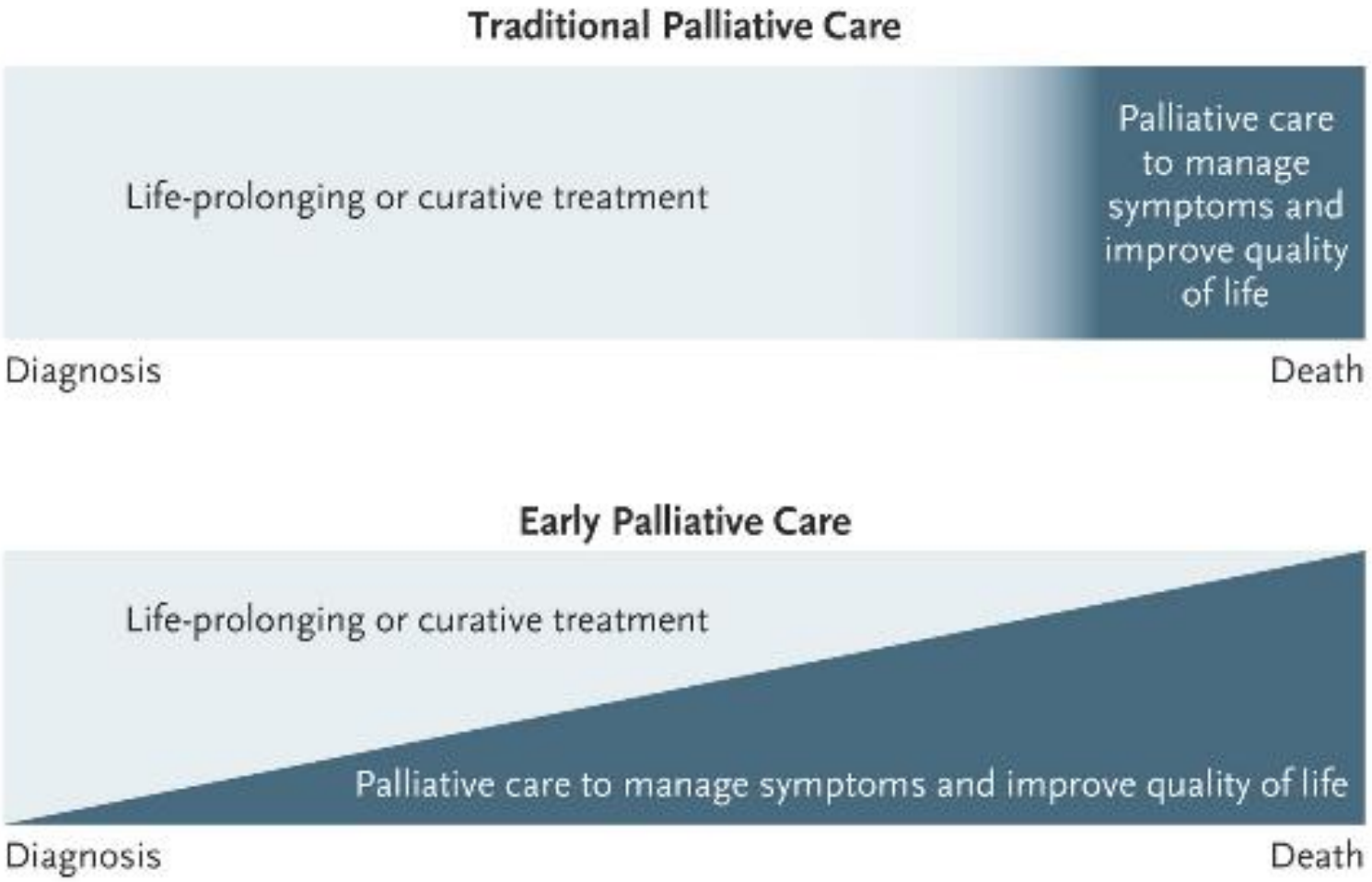
- Barrier: structural factors
  - Oversupply of resources for intensive, cure-focused care
  - Undersupply of palliative care, hospice resources
- Solution: increase access to palliative care
  - Increase availability of palliative care, hospice services
  - Shift the care delivery model: integrated, early concomitant palliative care

Palliative care: an expansive view

"Palliative care seeks to prevent, relieve, reduce or soothe the symptoms of disease or disorder without effecting a cure… Palliative care in this broad sense is not restricted to those who are dying or those enrolled in hospice programs… It attends closely to the emotional, spiritual, and practical needs and goals of patients and those close to them."

Institute of Medicine 1998

Shifting models of care



Parikh RB, Kirch RA, Smith TJ, Temel JS. Early specialty palliative care--translating data in oncology into practice. NEJM, 2013 12;369(24):2347-51.

Shifting gears: barriers and solutions

- Barrier: Patient and physician factors
  - Lack of Advance Care Planning (ACP), discussion of goals of care
  - Lack of knowledge about prognosis
  - "Denial"—i.e., "not getting it"

- Solution: increase provision of information
  - Patient and provider training in ACP
  - Decision support interventions
    - ACP, prognosis assessment

Smith TJ et al. A pilot trial of decision aids to give truthful prognostic and treatment information to chemotherapy patients with advanced cancer. J Support Oncol. 2011 Mar-Apr;9(2):79-86.

Smith TJ et al, Giving honest information to patients with advanced cancer maintains hope. Oncology (Williston Park) 2010 May;24(6):521-5.

Shifting gears: bigger, deeper barriers

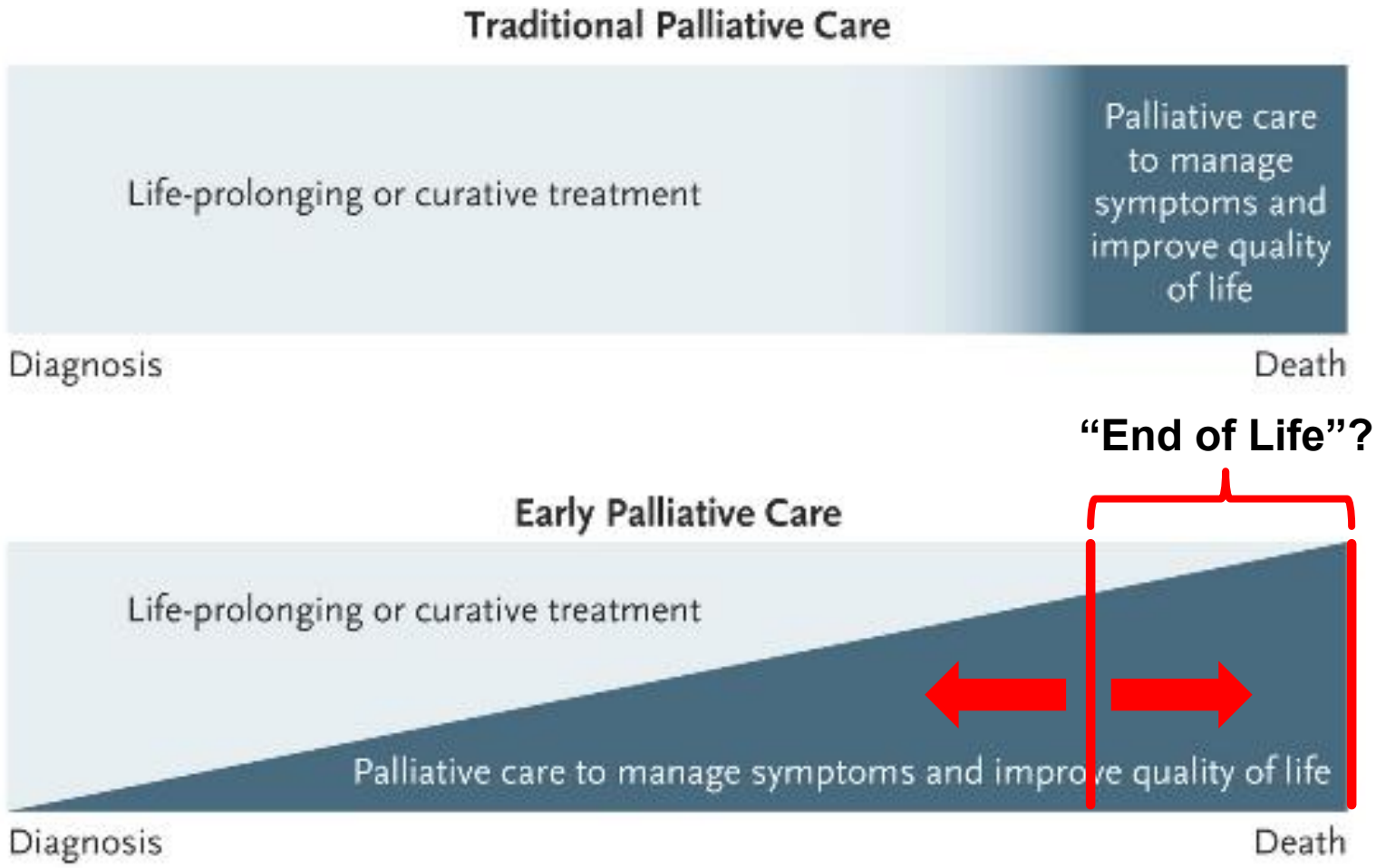
- Prognostic uncertainty
- Optimism bias

Shifting gears: prognostic uncertainty

- Difficulty determining prognosis
  - Limited prognostic evidence (epistemic uncertainty)
  - Limited applicability of prognostic estimates at individual, single-event level (aleatory uncertainty)
- Difficulty determining when "end of life" begins
  - No clear bright lines, even if prognostic estimates were accurate
- An irreducible problem

Han PKJ. Conceptual, methodological, and ethical problems in communicating uncertainty in clinical evidence. *Med Care Res Rev*. 2013 Feb 70(1S): 14-36.

Shifting gears: when is "EOL"?



Parikh RB, Kirch RA, Smith TJ, Temel JS. Early specialty palliative care--translating data in oncology into practice. NEJM, 2013 12;369(24):2347-51.

Shifting gears: optimism bias

- *The inclination to overestimate the likelihood of encountering positive events in the future and to underestimate the likelihood of experiencing negative events* (Weinstein, Klein)
- An adaptive cognitive illusion: "…*protects us from accurately perceiving the pain and difficulties the future undoubtedly holds*…" (Sharot)
- An <u>essential</u> human need

Weinstein, ND. Unrealistic optimism about future life events. JPSP. 39(5), 1980, 806-820.

Weinstein, ND, Klein WM. 1996. "Unrealistic Optimism: Present and Future". *J Soc Clin Psychol* **15** (1): 1–8.

Sharot, T. The Optimism Bias. New York: Vintage. 2011

Shifting gears: insurmountable barriers

- Prognostic uncertainty + optimism bias
  - Irreducible, essential
- Magnify the propensity against shifting from cure- to palliation-focused care
  - Uncertainty opens the door to motivated reasoning: gives people "a chance"
  - Optimism bias makes both clinicians and patients less willing to acknowledge "EOL" phase, or to "give up" cure-focused treatment

Shifting gears: insurmountable barriers

- Failure to shift gears is not simply an issue of "misunderstanding," "denial"
  - Prognosis at the individual level is truly unknown: can we ever say (with certainty) that optimism is "unrealistic" or "irrational"?
  - People are optimistic because they have to be
- So prognostic information may help…but only so much
- Can't make uncertainty and optimism bias go away

Beyond information: essential tasks

- Cognitive reframing: "Hope for the best, prepare for the worst"
  - Acknowledge prognostic uncertainty
  - Acknowledge our own cognitive biases towards optimism
  - Adopt strategies to protect against dangers of optimism, but to benefit from its fruits (Sharot)
- How?
  - Better communication?
  - Relationship building, emotional support
  - Other strategies…more research is needed

Thank You

Questions/Comments, contact:
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