

# Incorporating Palliative Care Principles Into Home Care



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COLLABORATION FOR HOME CARE ADVANCES IN MANAGEMENT AND PRACTICE



This presentation was delivered by Mary Ersek, Associate Professor, University of Pennsylvania School of Nursing at the VNSNY Beatrice Renfield Lecture Series on Tuesday, April 7<sup>th</sup>, 2009

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# Objectives

- Describe the basic components of palliative care
- Discuss ways to incorporate palliative care approaches into non-hospice home care

# History of Health Care's Approaches to Dying

- Focus on disease and treatment = Death as defeat
- Death in hospitals, institutions
- Limits of medical technology, Cruzan and Quinlan cases
- Hospice movement



# Hospice care

- Hospice movement began as a grassroots consumer movement in response to the “medicalization” of death and dying
- First US hospice incorporated in New Haven, CT, 1971
- Hospice became a covered Medicare benefit in 1984; extended to nursing home residents in late 1980s



# Hospice includes:

- Interdisciplinary team, often led by a nurse case manager
- Physician services (although PCP generally directs medical care through hospice team)
- Medical appliances and supplies
- Drugs for symptom management and pain relief

# Hospice Services

- Regular, scheduled visits
- 24/7 availability to answer questions, solve problems, make visits
- Coaches caregivers
- Short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Emotional and spiritual support to patient and family
- Bereavement services to survivors

# Limitations of Traditional Hospice Programs

- Served mostly individuals with advanced cancer
- Focused on last 6 months of life
- Primary care setting: private homes
- Individuals were required to forego all curative therapies for eligibility

# Unmet Needs in Non-Hospice Settings

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 ORIGINAL CONTRIBUTION

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## Family Perspectives on End-of-Life Care at the Last Place of Care

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**Context** Over the past century, nursing homes and hospitals increasingly have become the site of death, yet no national studies have examined the adequacy or quality of end-of-life care in institutional settings compared with deaths at home.

**Objective** To evaluate the US dying experience at home and in institutional settings.

**Design, Setting, and Participants** Mortality follow-back survey of family members or other knowledgeable informants representing 1578 decedents, with a 2-stage probability sample used to estimate end-of-life care outcomes for 1.97 million deaths from chronic illness in the United States in 2000. Informants were asked via telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours.

**Main Outcome Measures** Patient- and family-centered end-of-life care outcomes, including whether health care workers (1) provided the desired physical comfort and emotional support to the dying person, (2) supported shared decision mak-



OVER THE PAST CENTURY, DYING has become increasingly institutionalized. In the early 1900s most

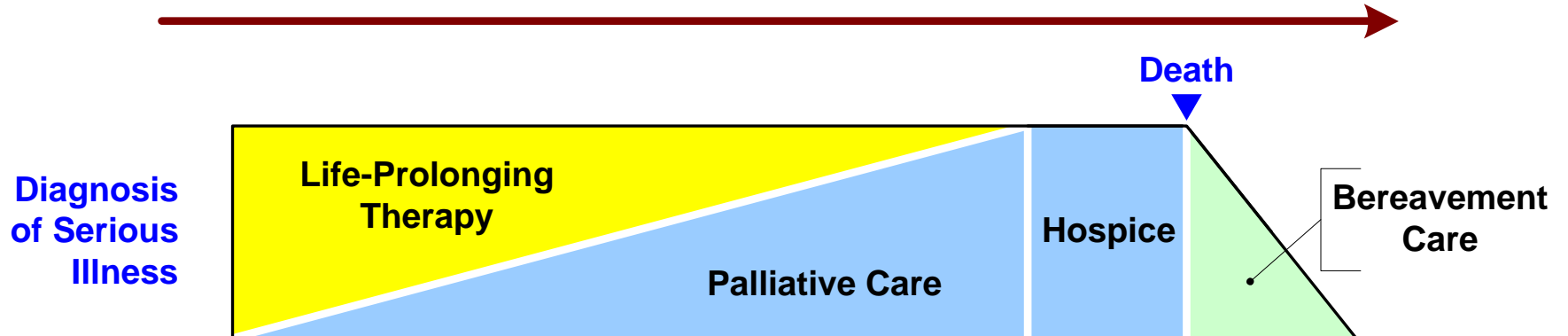
# Unmet Needs in Home Care (n=65)

Concern	Home Care without Hospice	Hospice
Pain	42.6	18.3
Dyspnea	38.0	25.6
Emotional support	70.0	34.6
Contact with MD	22.5	14.0
Treating patient with respect	15.5	3.8
Emotional support for family	45.4	21.1
Information about what to expect	31.5	29.2

# Emergence of Palliative Care

- Movement began in 1980s, gaining momentum throughout the 1990s
- Goal: to move hospice care “upstream”
- Brings palliative care to clinical settings other than the home
- Hospices expanded services
- Began largely as a movement in academic medicine
- National Consensus Project

## Palliative Care's Place in the Course of Illness



# National Consensus Project

## Eight Domains

1. Structure and Process of Care
2. Physical Aspects of Care
3. Psychological and Psychiatric Aspects of Care
4. Social Aspects of Care
5. Spiritual, Religious and Existential Aspects of Care
6. Cultural Aspects of Care
7. Care of the Imminently Dying Patient
8. Ethical & Legal Aspects of Care



<http://www.nationalconsensusproject.org/>

# Palliative Care Defined

Patient and family centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information and choice.

- CMS definition in proposed Medicare Hospice COPs
- Adopted by NQF in the *Framework* document

Care  
Coordination

Decision-making,  
Goal-setting

Communication

Pain &  
Symptom  
Management

Key Elements: Palliative Care

# The National Quality Forum: Framework for Hospice & Palliative Care

- Private, nonprofit membership organization created to develop and implement a national strategy for healthcare quality improvement
- Endorsed the NCP Guideline
- In 2006, published *A Framework for Palliative and Hospice Care Quality Measurement and Reporting*
- Articulated 38 “preferred practices” for hospice and palliative care services based on the 8 domains

# Joint Commission (TJC)

- Early 2008, TJC drafted voluntary palliative care elements of performance for specialized palliative care programs
- Currently, TJC embedded the domains and philosophy of the *NCP Clinical Guidelines for Quality Palliative Care* within the already established performance areas

# Palliative Care:

Not “if” but “how”?

