



# E L N E C

*End-of-Life Nursing Education Consortium*

Core Curriculum

## Module 1 Palliative Nursing Care

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## Death and Dying in America

- **Three major studies paint a grim picture of the experience of dying.**

Field & Cassel, 1997; Last Acts, 2002; SUPPORT, 1995

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## Death and Dying in America (cont.)

- Disparity between the way people die/the way they want to die
- Patient/family perspective

Egan-City & Labayak, 2010; Field & Cassel, 1997

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## The Need for Improved Palliative Care

- Late 1800's
- Early to mid 1900's

Field & Cassel, 1997; Saunders 2004

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# Cause of Death Demographic and Social Trends

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infectious Diseases	Chronic Illnesses
Death rate	1726 per 100,000 (1900)	800.8 per 100,000 (2004)
Average Life Expectancy	50	77.8
Site of Death	Home	Institutions
Caregiver	Family	Strangers Health Care Providers
Disease/Dying Trajectory	Relatively Short	Prolonged

Administration on Aging, 2000; Field & Cassel, 1997; Minino, et al, 2007

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# Differences in Cause of Death

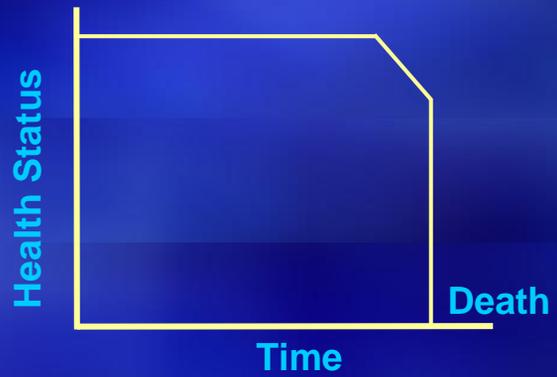
- Age
- Race
- Ethnic origin
- Disparities

Field & Cassel, 1997; Yabroff et al., 2004

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# Illness/Dying Trajectories Sudden Death, Unexpected Cause

< 10% (MI, accident, etc.)

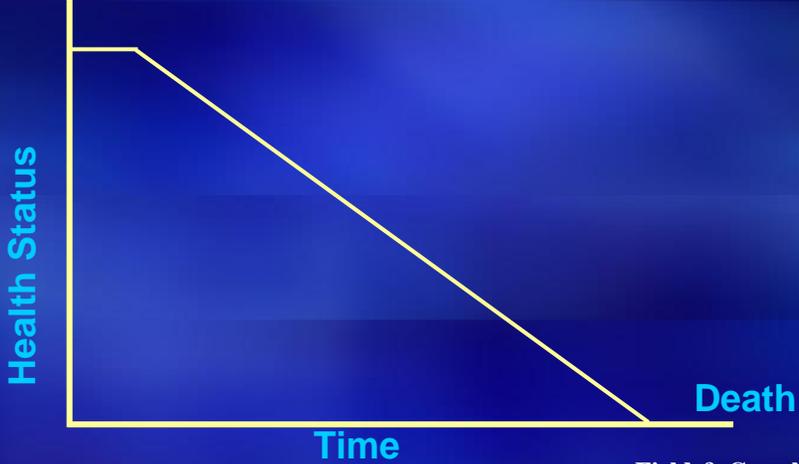


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Field & Cassel, 1997

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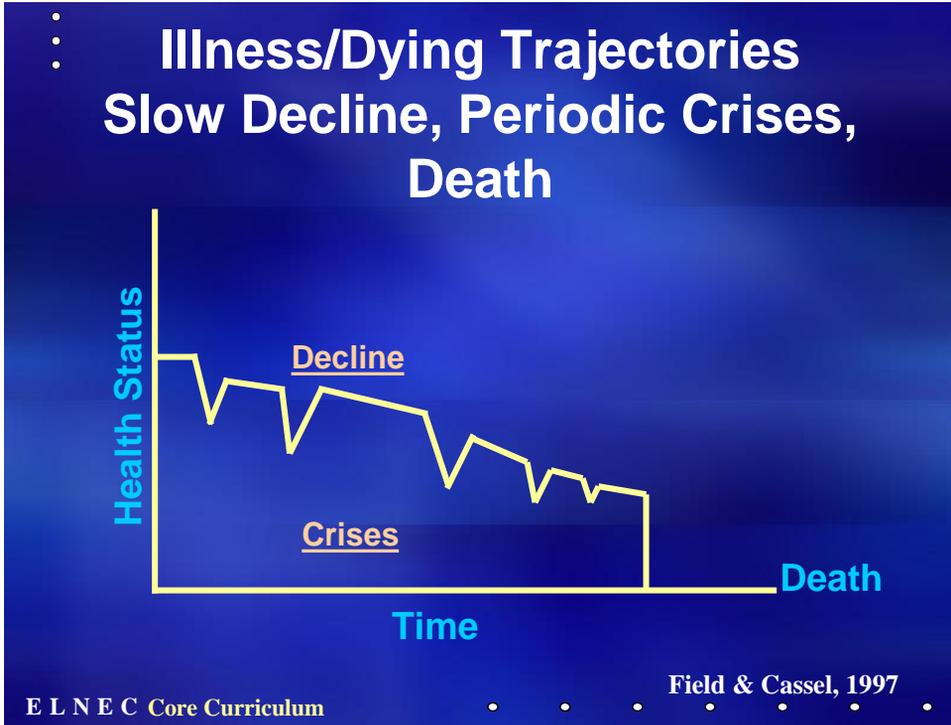
# Illness/Dying Trajectories Steady Decline, Short Terminal Phase



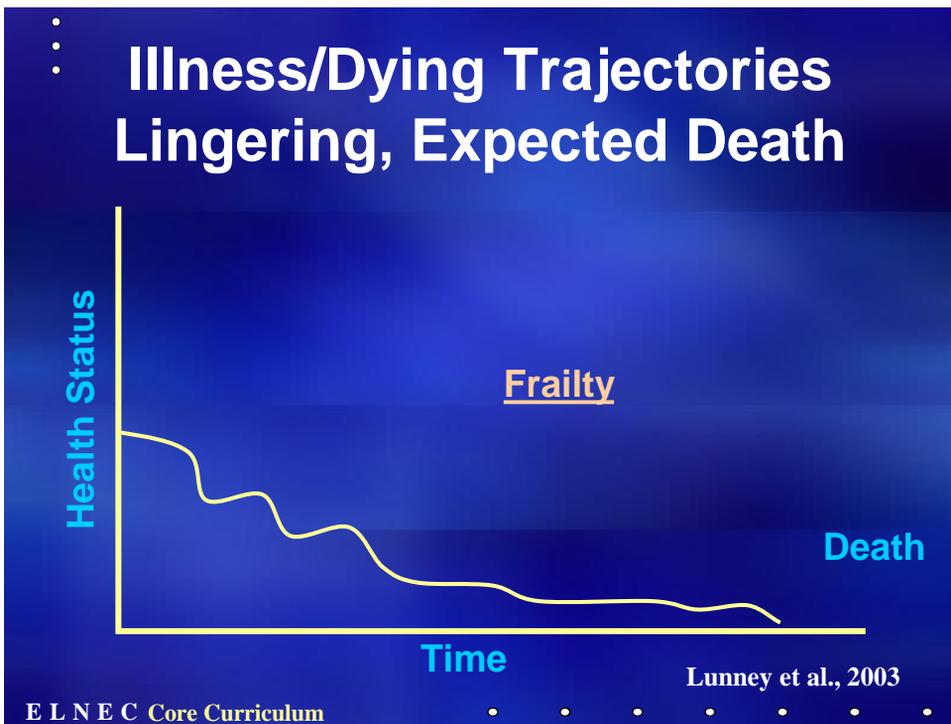
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Field & Cassel, 1997

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## Barriers to Quality Care at the End of Life

- Failure to acknowledge the limits of medicine
- Lack of training for healthcare providers
- Hospice/palliative care services are poorly understood
- Rules and regulations
- Denial of death

Glare et al., 2003; NHPCO, 2009

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## What is Hospice?

- Definition
- History



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## What is Palliative Care?

- Definition
- History



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## Hospice includes:

- Interdisciplinary care
- Medical appliances and supplies
- Drugs for symptom and pain relief
- Short-term inpatient and respite care
- Homemaker/home health aide
- Counseling
- Spiritual care
- Volunteer services
- Bereavement services

<http://www.nhpco.org>

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## Payment for Hospice and Palliative Care Services

- **Hospice:**
  - Medicare
  - Medicaid
  - Most private health insurers
- **Palliative Care:**
  - Philanthropy
  - Fee-for-service
  - Direct hospital support

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## Hospice Medicare Benefit Eligibility Criteria:

- The patient's doctor and the hospice medical director use their best clinical judgment to certify that the patient is terminally ill with life expectancy of six months or less, if the disease runs its normal course
- The patient chooses to receive hospice care rather than curative treatments for his/her illness
- The patient enrolls in a Medicare-approved hospice program

<http://www.nhpco.org>

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## General Principles of Palliative Care

- Patient and family as unit of care
- Attention to physical, psychological, social and spiritual needs
- Interdisciplinary team approach

[www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)

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## General Principles (cont.)

- Education and support of patient and family
- Extends across illnesses and settings
- Bereavement/grief support for families and staff

Panke & Ferrell, 2010; Corless, 2010

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# Current Practice of Hospice and Palliative Care

Curative Treatment

Palliative Care

Hospice

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# Continuum of Care

Disease-Modifying Treatment

Palliative Care

Hospice Care

Bereavement Support

Death

Terminal Phase of Illness

NQE, 2006

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## Let's Practice: A Case Study

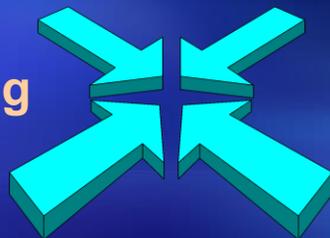
- 38 year-old male with sickle cell disease
- Had a stroke 8 months ago
- Lives in a skilled nursing facility
- Frequent exacerbations of pain over the past 6 months (8 hospitalizations)

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## Quality-of-Life Model

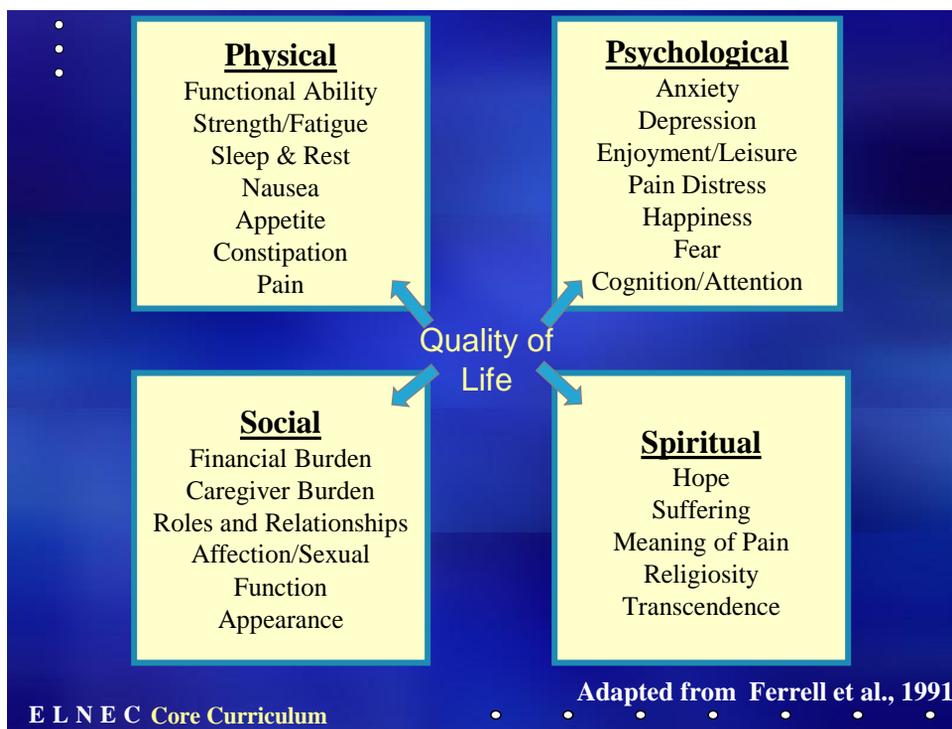
- Physical Well-Being
- Psychological Well-Being
- Social Well-Being
- Spiritual Well-Being



Ferrell et al., 1991

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## Maintaining Hope in the Midst of Death

- Experiential processes
- Spiritual processes
- Relational processes
- Rational thought processes

Ersek & Cotter, 2010

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## Tools and Resources for Palliative Care

### Assessment Tools

- Physical symptoms
- Emotional symptoms
- Spirituality
- Quality of life
- Caregivers outcomes

<http://prc.coh.org>

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## Prognostication

- Performance status  
Karnofsky – ECOG poor predictors
- Multiple symptoms
- Biological markers (e.g. albumin)
- “Would I be surprised if this patient died in the next 6 months?”
- Lynn et al., 2000

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## Role of the Nurse in Improving Palliative Care

- Some things cannot be “fixed”
- Use of therapeutic presence
- Maintaining a realistic perspective



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## Extending Palliative Care Across Settings

- Nurses as the constant
- Expanding the concept of healing
- Becoming educated

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## Final Thoughts.....

- Quality palliative care addresses quality-of-life concerns
- Increased nursing knowledge is essential
- “Being with”
- Importance of interdisciplinary approach to care

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*To Comfort Always*

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