Pediatric Curriculum

**MODULE 1: INTRODUCTION TO PEDIATRIC PALLIATIVE CARE**
Pediatric Health Care

- Late 1800's
- Early to mid-1900's
- History of pediatrics
- Patient Protection & Affordable Care Act, 2010
Child Health Sub-populations

- **Population of Children Under 18**: 73,600,000
  - **Children with Special Health Care Needs**: 11.2 million
    - **Children with Life Threatening Conditions**: 500,000
      - **Child Deaths**: 42,328 deaths in children ages 0-19 years
        - (15,500 Neonatal with 7800 Infant deaths)
          - CDC, 2016
        - Federal Interagency Forum, 2017
Pediatric Death

- Death in developing countries
- Death in the United States
Disease/Dying Trajectories

- Sudden, unexpected death
- Death from potentially curable disease
- Death from lethal congenital anomaly
- Death from progressive conditions with intermittent crises
Site of Pediatric Death

- Institutions
  - Hospitals, LTCF, inpatient hospice
- Intensive care units
- Emergency room
- Home care
Definition of Palliative Care

“An approach that improves the quality of life (QOL) of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”

Wolfe et al., 2011
Pediatric Palliative Care

Disease-Modifying Treatment

Palliative Care

Hospice Care

Bereavement Support

Terminal Phase of Illness

Death
What is Hospice?

- Hospice care is a medical benefit covered by Medicaid and private insurances

- Patients with a life-expectancy of 6 months or less
  - “Would you be surprised if this child died in the next 6 months?”
Why Hospice?

Benefits:

- Nursing care
- Medical equipment
- Pain and symptom management
- Home based social work
- Chaplain and hospice aid services
- Respite care
- Home delivery of many medications
- Allows the child to stay home for care
- Bereavement support for the family after the death
- Additional support to the family in their home
Changing Landscape of 2010

**Affordable Care Act**

- Section 2302: Concurrent Care for Children Requirement (CCCR)
- Removed the prohibition of receiving curative treatment for any eligible child with Medicaid or Children’s Health Insurance Program (CHIP)
- To be eligible
  - < 21 years of age
  - Physician certifies the child is within the last 6 months of life
  - Entitled to any other services to which the child is entitled under Medicaid for treatment of the terminal condition
Philosophy and Goals of Hospice and Palliative Care

- Philosophy of care
- Goals of care
Principles of Hospice & Palliative Care for Children

- Child and family as unit of care with attention to caregiver support
- Adolescents and young adults have distinctive needs
- Attention to physical, psychological, social, and spiritual needs
Principles of Hospice and Palliative Care for Children (cont.)

- Interdisciplinary team approach
Principles of Hospice and Palliative Care for Children (cont.)

- Education and support of child and family
- Extends across illnesses and settings
- Bereavement support
Models of Pediatric Palliative and/or Hospice Care

- Hospital-based programs
- Free-standing facility
- Hospice-based programs
- Community agency or long-term care facility
Massachusetts Pediatric Palliative Care Network: Implementation of State-Funded Program

- Consult services
- Decreased cost
- 100% of deaths occurred at family’s requested location
- Median length of stay on service = 233 days

Bona et al., 2011
Death and Dying Disparities

- Child perspective
- Family perspective
- Sibling perspective
- Grandparents perspective
- Community perspective
- Schools
Development Issues in Pediatric Palliative Care

- Comprehension
- Communication
- Fears
- Development theories & tools
- Child’s need to protect family
Stages of Development

- Infancy
- Toddler
- Preschool Age
- School Age
- Adolescence
Barriers to Quality Care at the End of Life

- Uncertainty of prognosis
- Delayed access to hospice/palliative care
  - Death denial
- Overtreatment
- Communication breakdown
- Insensitivities to cultural concerns
Barriers to Quality Care at the End of Life (cont.)

- Lack of adequate training of professionals

- Other limitations
  - Opioid prescribing regulations
  - Financial
  - Geographical
Nurse's Role in Pediatric Palliative Care

- Anticipating
- Preventing
- Treating
- Promoting
- Advocating
Nurses Role in Pediatric Palliative Care (cont.)

- The importance of presence
- Nurses as the safety net
- Redefining hope
Hope Within Pediatric Palliative Care

- Meaning of hope
- Hope vs. despair
- Role of hope
Model of Quality of Life (QOL)

- Physical Well-Being
- Psychological Well-Being
- Social Well-Being
- Spiritual Well-Being
**Physical**
- Functional Ability
- Strength/Fatigue
- Sleep & Rest
- Nausea
- Appetite
- Constipation
- Pain

**Psychological**
- Anxiety
- Depression
- Enjoyment/Leisure
- Pain Distress
- Happiness
- Fear
- Cognition/Attention

**Social**
- Financial Burden
- Caregiver Burden
- Roles & Relationships
- Affection/Sexual Function
- Appearance

**Spiritual**
- Hope
- Suffering
- Meaning of Pain
- Religiosity
- Transcendence

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Quality of Life

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**ELNEC Pediatric**
Suffering

- State of severe distress that threatens intactness of the person
- Failure to respond to needs intensifies suffering
- Depth of suffering

Ferrell & Coyle, 2008