Core Curriculum

MODULE 1
PALLIATIVE NURSING CARE
Objectives

- Describe the **role of the nurse** in providing quality palliative care for patients across the lifespan.

- Identify the need for **collaborating with interdisciplinary team members** while implementing the nursing role in palliative care.

- Recognize changes in **population demographics, healthcare economics, and service delivery** that necessitate improved professional preparation for palliative care.

- Describe the **philosophy and principles of hospice and palliative care** that can be integrated across settings to affect quality care at the end of life.

- Discuss aspects of assembling physiological, psychological, spiritual, and social domains of **quality of life** for patients and families facing a life-threatening illness or event.
Section I: Overview of Dying in America

Nurses Play a Major Role in Caring for Seriously Ill Patients and Their Families

- Elicit goals of care
- Assess, manage, and coordinate care
- Listen to patients/family members
- Bear witness
- Communicate with all members of the interprofessional team
- Knowledgeable in evidence-based practice

NOTE: Supported by the American Nurses Association (ANA) and the Hospice and Palliative Nurses Association (HPNA)
The Facts About Dying in America Today

- 117 million adults have 1 or more chronic diseases
- 1 out of 4 adults have 2 or more chronic diseases
- Over 2.6 million people die/year in the US
- Top 5 leading causes of death
  - Heart disease (633,842)
  - Cancer (595,930)
  - Chronic lower respiratory disease (155,041)
  - Unintentional injuries (146,571)
  - Cerebrovascular diseases (140,323)

CDC, 2017
Serious Illness in America: Its Impact on Care

- Exploding healthcare costs
- Poor understanding of prognosis
- Failure to treat pain and other symptoms
- Increased use of technology

CHCF, 2017; Lui et al., 2014
Impact of Chronic Illness on Patients and Families

- Prolonging life but promoting suffering?
- Burdens versus benefits?
What Constitutes Quality Care at the End-of-Life?

- For Healthcare Teams: providing symptom management and discussing the emotional aspects of the disease

- For Patients: achieving a sense of control, attaining spiritual peace, succeeding in having finance in order, strengthening relationships with loved ones, and believing that their life has meaning
Illness/Dying Trajectories Sudden Death, Unexpected Cause

< 10% (MI, accident, etc.)

Health Status

Time

Death

Illness/Dying Trajectories Steady Decline, Short Terminal Phase

Health Status

Time

Death

Illness/Dying Trajectories Chronic Illness, Periodic Crises, Death

Health Status

Decline

Crisis

Time

Death

Illness/Dying Trajectories, Progressive Deterioration Expected Death

Health Status

Frailty

Time

Death
Overview of Caregivers: Their Commitment and The Cost

- Most adults prefer to die at home, generally requiring family to provide support
- Caregiving can increase risk of premature death for the caregiver
- Cost of uncompensated care= $450 B/year

NIH, 2017; RAND, 2014; Rothman, 2014
Remember Patients Who Are Veterans

- U.S. Veterans: 21 million
- 96% of all veterans die in non-VA facilities
- 430 WWII veterans die each year
- Veteran deaths account for almost 28% of all U.S. deaths
- Nearly 40% of enrolled veterans live in rural communities
- 121,000 veterans are without shelter or healthcare, hence no access to hospice of palliative care

Section II: Defining Hospice and Palliative Care

What is Hospice?

- Definition
- History
- Hospice services
- Statistics
What is Palliative Care?

- Palliative care means 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.

NCP, 2013; NQF, 2008
Current Practice of Hospice and Palliative Care
Continuum of Care

- Disease-Modifying Treatment
- Palliative Care
- Terminal Phase of Illness
- Hospice Care
- Bereavement Support
- Death
Snapshot of Palliative Care in the US Today

- 67% of US hospitals have palliative care programs
- 90% of hospitals with 300 beds or more have palliative care teams
- 56% of hospitals with less than 300 beds have a palliative care program

National Palliative Care Registry™, 2017
### Characteristics of Palliative Care Philosophy and Delivery

- **Interdisciplinary care**
- **Excellent communication between patients, families, health care providers**
- **Services provided concurrently with or independent of curative/life-prolonging care**
- **Hopes for peace and dignity are supported throughout the course of illness and pre-post dying process**

NCP, 2013
Barriers to Quality Care at the End of Life

- Failure to acknowledge the limits of medicine
- Workforce that is too small to meet demands
- Lack of training for healthcare providers
- Hospice/palliative care services are poorly understood
- Lack of research
- Lack of payment models linked to quality measures
- Rules and regulations
- Denial of death

CAPC, 2015; NHPCO, 2014 & 2015
Lessons Learned in Managing Barriers

- Give providers “the language”
- Build collaborative relationships with palliative care team
- Institute automatic triggers for palliative care consult

Lindvall et al., 2014
Prognostication Is Difficult: Can Cause Confusion as to When to Initiate Palliative Care

- Four principles of survival prediction:
  - It is a process
  - Evolves over the disease trajectory
  - Accuracy varies by definition, population, and time
  - Exact time of death cannot be predicted accurately

- 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?”

Hui, 2015; Lynn et al., 2007
Stop and Consider

Which of the following patients could benefit from palliative care?

A. 64-year-old with congestive heart failure, hypertension and diabetes
B. 32-year-old with acute myelogenous leukemia
C. 57-year-old with newly diagnosed amyotrophic lateral sclerosis
D. 76-year-old with Parkinson’s disease
Section III: Resources for Making the Case to Provide Excellent Palliative Care

Changes Must Be Made: Development of Standards to Guide Practice

- Institute of Medicine (IOM)
- National Consensus Project (NCP) for Quality Palliative Care
- National Quality Forum (NQF)
- The Joint Commission
- American Association of the Colleges of Nursing (AACN), *Competencies and Recommendations for Education Undergraduate Nursing Students (CARES)*
### NCP and NQF: 8 Domains of Palliative Care

<table>
<thead>
<tr>
<th>Domain</th>
<th>Description</th>
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<tbody>
<tr>
<td>Structure and processes of care</td>
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<td>Physical aspects of care</td>
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<td>Psychological and psychiatric aspects of care</td>
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<td>Social aspects of care</td>
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<tr>
<td>Spiritual, religious, and existential aspects of care</td>
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<td>Cultural aspects of care</td>
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<td>Care of the patient at the end of life</td>
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<td>Ethical and legal aspects of care</td>
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NCP, 2013
Nursing & Medical Organizations That Support Palliative Care

**NURSING**
- American Association of Nursing (AACN)
- American Association of Critical Care Nurses (AACN)
- Hospice & Palliative Nurses Association (HPNA)
- Oncology Nursing Society (ONS)
- American Nephrology Nurse’s Association (ANNA)

**MEDICINE**
- American Academy of Hospice & Palliative Medicine (AAHPM)
- American Heart Association (AHA) & American Stroke Association (ASA)
- American Society of Clinical Oncology (ASCO)
- American Thoracic Society (ATS)
Pivotal Study

- Population: patients with metastatic non-small cell lung cancer

- Design:
  - ½ received palliative care and standard oncology care
  - ½ received standard oncology care only

- Conclusion: Those who received early palliative care along with standard oncology care
  - Increased both quality of life and mood
  - Less aggressive care
  - Longer survival

Temel et al., 2010
Sutter Health: Advanced Illness Management (AIM)

- Fewer hospitalizations, greater savings
- Improved patient and family satisfaction
- 58% fewer hospital admissions
- 69% reduction in ICU days

Result: Savings of > $60 million for payers

Sutter Health, 2016
Does Palliative Care Improve Care, Decrease Hospitalizations, and Save Money?

- ↓ Hospitalizations
- ↓ ICU admissions
- Palliative care triggers
- ↓ ED visits
- ↓ Costs

CAPC, 2017b
What about Costs for Medicare and Medicaid Patients?

- The seriously ill constitute only 5-10% of patients (more than ½ of the nation’s total healthcare costs)
- 10% of Medicare beneficiaries with 5 or more co-morbid illnesses (2/3 of total Medicare spending)
- The 4% of the sickest Medicaid beneficiaries (48% of total program spending)
- 76% of the national Medicaid budget goes to acute hospital services, the most expensive setting of care

_Palliative care could decrease these expenditures_

CAPC, 2016
Payment for Hospice and Palliative Care

**HOSPICE**
- Medicare
- Medicaid
- Most private health insurers

**PALLIATIVE CARE**
- Philanthropy
- Fee-for-service
- Direct hospital support
Quality-of-Life Model

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 and Relationships
Affection/Sexual Function
Appearance

Spiritual
Hope
Suffering
Meaning of Pain
Religiosity
Transcendence

Quality of Life

http://prc.co.h.org
Hope for the Best…Prepare for the Worst

- **Hope for the best**
  - Review treatments that may prolong life and relieve suffering

- **Prepare for the worst**
  - What would be left undone?
  - Who would make decisions if you could not make them?
  - What would your wishes be regarding aggressive treatments, such as resuscitation?
Maintaining Hope in the Midst of Death

Experiential processes

Remember the caregiver

Spiritual processes

Rational thought processes

Relational processes

Cotter & Foxwell, 2015
Tools and Resources for Palliative Care

Assessment Tools

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

http://prc.coh.org
Role of the Nurse in Improving Palliative Care

- Some things cannot be “fixed”
- Use of therapeutic presence
- Maintaining a realistic perspective
Extending Palliative Care Across Settings

- Nurses as the constant
- Expanding the concept of healing
- Becoming educated
- Joint Commission Advanced Certification in Palliative Care
Final Thoughts.....

- Quality palliative care addresses quality-of-life concerns
- Increased nursing knowledge is essential
- “Being with”
- Importance of interdisciplinary approach to care
“... touching the dying, the poor, the lonely, and the unwanted according to the grace we have received, and let us not be ashamed or slow to do the humble work.”

-Mother Teresa