Evolving Treatment Options in Lung & Breast Cancer Palliative Care

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Palliative Care an Introduction and ELNEC

- The End-of-Life Nursing Education Consortium (ELNEC) Project is a national end-of-life educational program administered by City of Hope (COH) and the American Association of Colleges of Nursing (AACN) designed to enhance palliative care in nursing. The ELNEC Project was originally funded by a grant from the Robert Wood Johnson Foundation. Additional funding has been received from the Cambia, Millbank, Oncology Nursing, Open Society, Aetna, Archstone, California HealthCare, and Stupski Foundations, American Association of Colleges of Nursing, National Cancer Institute (NCI), US Cancer Pain Relief, and the Department of Veterans Affairs (VA). Materials are copyrighted by COH and AACN and are used with permission.

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Objectives

- Describe current **trends in oncology care today**
- Articulate **key issues** for patients, families, and healthcare systems related to cancer diagnosis, treatment, goals of care, etc.
- Describe the **role of the nursing professional** 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
- Identify the importance of **pain assessment and management in cancer patients**

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Sounds Familiar?

- Today, for the first time, you are seeing a new patient, Terry, a 43 years old woman with metastatic breast cancer (HER2neu positive). She has received doxorubicin, paclitaxel, and trastuzumab, radiation to name a few treatments, in a small community clinic. Because she has been dissatisfied with her experience at a previous clinic, she decides to seek treatment at your facility and states:
  - “My pain is inadequately treated”
  - “I am having trouble breathing because of tumors in my lungs-I have made 3 trips to he ER in the past month”
  - “My care seems disorganized/fragmented and rushed”
  - “ I am becoming a tremendous burden to my husband and mom, who are trying to assist me and our 4 children”
  - “All I want is to be able to be independent and to have my symptoms under control”
  - “I just want someone to be honest with me about what my future looks like”

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PAIN

National Comprehensive Cancer Network (NCCN)

"There is increasing evidence in oncology that survival is linked to symptom control and that pain management contributes to broad quality-of-life improvement. To maximize patient outcomes, pain management is an essential part of oncological management."

NCCN, 2018

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ONS Position on Cancer Pain

- Pain prevention and treatment are essential elements of quality cancer care
- All people with cancer have a right to optimal pain relief
- Combination therapy is the standard of care
- Multidisciplinary and a collaborative effort is required

June, 2017 supplement dedicated to pain management for those with cancer.
https://cjon.ons.org/cjon/21/3/supplement

ONS, 2017

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Patients: Why is Their Cancer Pain Not Better Addressed/Managed?

- Fear cancer has progressed/recurred
- Not wanting to appear “weak” and have treatment reduced
- Not wanting to “distract” their provider
- Not wishing to appear to be drug-seeking
- Patients may believe that everything is being done to relieve their pain

Syrjala et al., 2014

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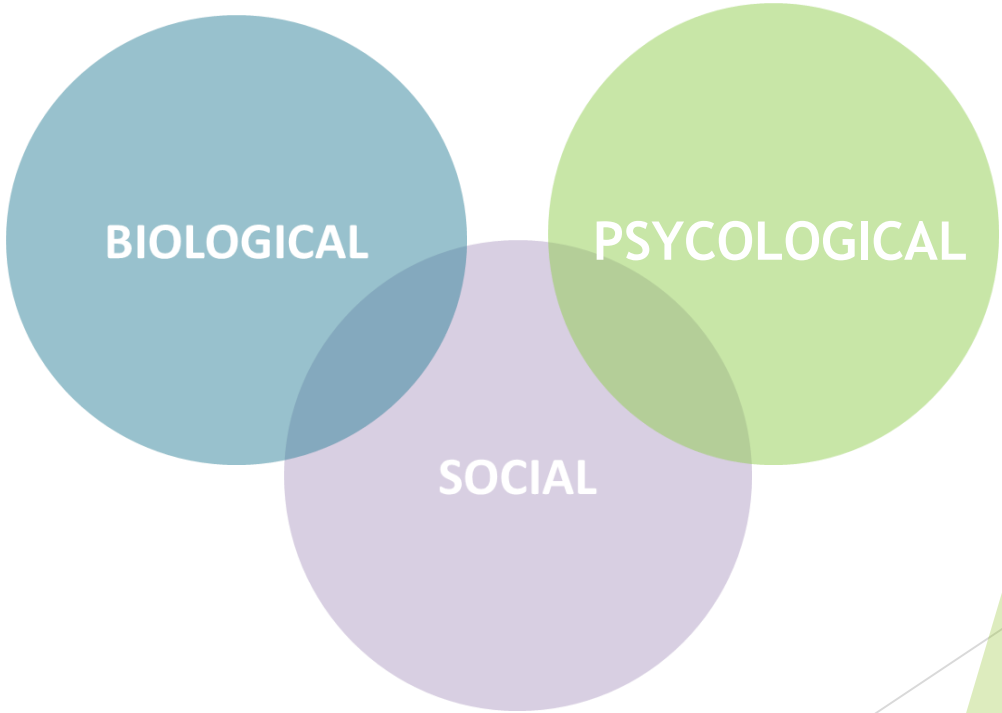
PAIN

- Pain is an unpleasant sensory and emotional experience, associated with actual or potential tissue damage.
- Pain is what ever the patient says it is occurring, when they say it does.



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Types of Pain

Etiology	Time	Disease or Condition
Nociceptive Neuropathic Visceral	Acute Chronic (persistent) Acute on chronic	Cardiac Pulmonary ESRD ESLD HIV/AIDS Brain tumors Neurologic Immunocompromised Endocrine

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Pain in Cancer Survivors

- Overall prevalence of pain in cancer survivors ranges from 5 - 41%
- 5%-10% experience severe chronic pain that interferes with functioning
- Usually related to treatment
- Survivor risk for recurrent or second cancers means new or worsening pain must be evaluated

Glare et al., 2014; Kurita & Sjogren, 2015; Paice et al., 2016a & 2016b; van den Beuken-van Everdingen, 2012

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So Where Would You Begin?

- Building a trustful relationship with Terry?
- Addressing pain and other symptoms?
- Collaborating with the interdisciplinary cancer team?
- Assessing her caregivers/family and their needs?
- Reviewing support systems?
- Contacting the palliative care team?

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Terry Showcases Common Needs of Cancer Patients: Are You Prepared to Communicate With Terry About These Needs?

Wants to maintain a sense of control

Wants to know life has meaning

Wants HOPE

Wants to know pain and symptoms will be well-managed

Steele & Davies, 2015

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Assessment History Questions

- Acute vs. chronic
- Location(s)
- Intensity
- Quality
- Pattern
- Aggravating, alleviating factors
- Function
- Goals for treatment

- Past and present medication use – efficacy and adverse effects
- Emotions/suffering
- Perception of pain

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Functional Assessment

- Functional Assessment
- Self care – grooming, toileting
- Walking – altered gait
- Cooking/food preparation/eating
- Work – disability
- Driving – neuropathy, vision, opioids/other sedating medications
- Reassess

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The State of Cancer in America

- **1.7 million+** new cancer diagnoses in children and adults in 2018 (4,626 new diagnoses/day)
- **609,640** people with cancer expected to die in 2018 (1,670/day)
- >**15.5 million** cancer survivors
- **0.9%**: The rate of decline of cancer incidence over the past decade
- **27 new drugs/biologics** were approved by the FDA in 2017 (11 hematology, 16 oncology)
- **47%** were diagnosed from the four most common cancers: breast, lung and bronchus, prostate, and colon and rectum
- Cancer was the leading cause of death in 22 states in 2016 and is projected to overtake cardiovascular disease as the leading cause of death by 2020

ACS, 2018; ASCO, 2017; Center Watch, 2017

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Cancer and Children (ages 0-14 years)

- Incidence: Cancer rates have slowly increased by 0.6% per year since 1975
- 10,590 new cancer diagnoses in 2018
- 1,180 cancer deaths are expected to occur among children in 2018

ACS, 2018

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Impact of Cancer Treatment

- Makes you ill before you are well – fraught with side effects
- Complex coordination of care is required
  - Surgeons
  - Radiation/medical oncology
  - Pain management
  - Palliative care
  - PCP's attending to other co-morbidities
- Oral therapy is increasingly becoming treatment of choice
- Medication adherence concerns

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The Facts: The Cost of Cancer Care

- In 2015, over $80.2 billion was spent on direct health care costs for cancer
- 52% of the costs represented outpatient/clinic provider visits
- 38% of the costs represented inpatient hospital stays
- Indirect cost of cancer diagnosis: lost wages, insurance cost and others.

ACS, 2018

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Stressors in Oncology Practices Today

According to a 2017 ASCO survey, the top 3 pressures in oncology practices today are:

- **Increasing practice/facility expenses**
- **Drug pricing**
- **EHR implementation/use**

ASCO, 2017

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Oncology Nurses and APRN Roles in Assessing/Managing Common Concerns

- **Physical**
  - Symptoms associated with treatment(s)
  - Symptoms associated with the disease
- **Psychological**
  - Anxiety
  - Depression
  - Many uncertainties
- **Social**
  - Financial concerns
  - Isolation
  - Dependence on others
  - Appropriateness of place of care
  - Sexuality
- **Spiritual**
  - Religious concerns
  - Existential needs
  - Hope

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Caring for the Person with Cancer: The Caregiver

- Typical caregiver
  - 49 year-old female
  - Providing care for 4 years on average
  - Spending 24.4 hrs/week
  - ADLs, running errands, managing finances, wound care, giving medications, etc
  - Unpaid- no outside support
  - Works full-time
  - Average household income =$54,700

AARP, 2015

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Survivorship Issues

- 14 million cancer survivors in the US today, with numbers rising
- Many experience long-term effects from their cancer and treatment(s), that may be unrecognized/not addressed by the healthcare team
- Recognizing those at highest risk for recurrence and second cancers is a priority

Halpern & Argenbright, 2017; Tralongo et al., 2017

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Dying in America – Improving Quality and Honoring Individual Preferences Near End of Life

Five areas for quality palliative care:

1. Delivery of person-centered and family-focused palliative care
2. Clinician-patient communication and advance care planning
3. Professional education in palliative care
4. Policies and payment for palliative care, and
5. Public education and engagement in palliative care

APRNs are involved in all of these areas and can improve care

Institute of Medicine, 2014

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Survivorship Issues

- Palliative care interventions **early** in the follow-up of unrelieved symptoms in cancer survivors will improve the quality of life of these patients.
- Coordinated palliative care and survivorship programs can improve long-term outcomes including social support, nutritional, rehabilitative and fertility preservation

Halpern & Argenbright, 2017; Tralongo et al., 2017

Does your cancer setting provide a coordinated program of both palliative care and survivorship programs to improve care to those surviving cancer?

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Is Palliative Care a "Fit" for Oncology? What are the Barriers to This Care?

- Public is not informed of these services and/or believes palliative care is end-of- life care
- Healthcare organizations are reluctant to change systems of care
- "Cure-at-all-cost" vs. "care" mentality
- Oncology workforce is not educated in palliative care

Which of these barriers do you see most often in your practice?

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According to the National Cancer Institute…

"Palliative care is given throughout a patient's experience with cancer. It should begin at diagnosis and continue through treatment, follow-up care, and the end of life".

NCI, 2010

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ASCO position

- Palliative care (PC) concurrent with usual oncology care is now the standard of care that is recommended for any patient with advanced cancer to begin within 8 weeks of diagnosis on the basis of evidence-driven national clinical practice guidelines; however, there are not enough interdisciplinary palliative care teams to provide such care.

Journal of Oncology Practice, ascopubs.org/doi/full/10.1200/JOP.2017.022939.

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Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

- The 2014 Institute of Medicine (IOM) report highlights the specific needs:

  Barriers in access to care
  - Mismatch between the services patients and families need and the services they can obtain
  - Improving the quality and availability of medical and social services for their patients and their families
  - Inadequate numbers of palliative care specialists and too little palliative care knowledge among other clinicians
  - Fragmented care delivery system, spurred by perverse financial incentives, that contributes to the lack of service coordination across programs and sustainable growth in costs

IOM, 2014

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ONS Position Statement

- Statement includes comments in response to the 2014 IOM report *Dying in America: Improving Quality of Honoring Individual Preferences Near End of Life*
- A thorough list of statements about the critical role oncology nurses play in providing palliative care. For example:
  - **All patients with cancer benefit from palliative care**
  - Palliative care **should begin at the time of diagnosis and continue through bereavement**

More information: https://www.ons.org/advocacy-policy/positions/practice/palliativecare

ONS, 2017

National Pediatric Organizations Provide a Joint Statement Supporting Palliative Care

National Association of Neonatal Nurses (NANN), Association of Pediatric Hematology/Oncology Nurses (APHON), and Society of Pediatric Nurses (SPN) promote *Precepts of Palliative Care for Children, Adolescents and Their Families*

https://www.napnap.org/sites/default/files/userfiles/about/PalliativecarePS_support.pdf

aphon
Association of Pediatric Hematology/Oncology Nurses

National Association of Neonatal Nurses

spn
SOCIETY OF PEDIATRIC NURSES

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Let's Hear from A Cancer Patient Who is Receiving Palliative Care

https://www.youtube.com/watch?v=9GRl9r6elJ0

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The Facts About Palliative Care Today

- 2/3 of US hospitals have a palliative care service
- Oncologists rank #4 in referring cancer patients to palliative care
  - Hospital Medicine: 53%
  - Internal/Family Medicine: 12%
  - Pulmonary/Critical Care: 12%
  - **Oncology: 7%**
- Yet, patients with cancer far exceed the population seen by palliative care (27%)—compared to cardiac (13%), complex chronic illness (6%), dementia (5%)
- Access to palliative care in the community (home, nursing home, assisted living) is limited for people who are not hospice-eligible

CAPC, 2016

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Oncology APRN's/ RN's Role

- One of 2 roles:
  - **Specialist in Palliative Care:** Provided by an APRN/RN with palliative care education and certification and focuses on patients/families with more complex needs/advanced illness
  - **Provider of Primary Palliative Care:** Because palliative care is embedded in nursing practice, all APRNs/RN's practice palliative care through giving attention to and alleviating suffering, promoting advocacy efforts, providing psychosocial and spiritual support, and using their skills to assess and assist in advance care planning

Wholihan & Tilley, 2016

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The Future of Advanced Practice Nursing in Palliative Oncology Care

- A 2009 report by the IOM/National Cancer Policy Forum outlined the future needs of the oncology workforce
- Embedded in that report are predictions from the American Society of Clinical Oncology (ASCO) that by 2020:
  - A 48% increase in cancer incidence will occur
  - An 81% increase of people living with/surviving cancer
  - Yet, only a 29% increase in the number of oncologists

Ferrell et al., 2017; IOM, 2009; Yang et al., 2014

Who will provide this care?

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Examples of Oncology APRNs/RN's Implementing Structure and Processes of Care

- Oncology team meets weekly with palliative care team to review patients who could benefit from palliative care (i.e. those with poor pain and symptom management, family/caregiver issues, etc)

- Cancer center provides a palliative care/symptom management clinic every Tuesday, led by an APRN/RN.

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Examples of Oncology APRNs/RN's Implementing Structure and Processes of Care

- Oncology APRN /RN's and social worker provide a 1-hour support group for caregivers 2x/week

- Procedure developed and instituted by Oncology APRN/RN: When a cancer patient dies on the unit and the family is ready to leave the hospital, the nurse who cared for the patient escorts the family to their car, taxi, etc, so the family does not have to leave the hospital alone.

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Examples of Oncology APRNs Implementing Structure and Processes of Care (cont)

- Oncology APRN provides an interdisciplinary ELNEC training course twice a year for staff. All staff must attend this course within 1-year of hire.
- Within 2 weeks AND 12-months of a patient dying, the social worker sends a bereavement card to the family.
- Every 6 months the APRN and chaplain organize a memorial service, inviting family/friends of those who have lost loved ones within those 6 months. Tea/coffee and cookies are donated by a local bakery.

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Let's Talk…

- You first met Stephen, age 14 years, 2 weeks ago when he was admitted to the pediatric oncology unit with a diagnosis of acute myelogenous leukemia (AML). He received his induction chemotherapy immediately upon being admitted and is now neutropenic. His medical team is concerned about his response thus far to treatment and to some new cardiac effects. He started running a fever and became hypotensive this afternoon, so has been transferred to PICU, suspecting sepsis.

- Palliative care has not been called to see Stephen nor his parents.

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Let's Keep Talking…

- What are your thoughts about a palliative care consult at this time?
- If so, how would you orchestrate the beginning of this consult?
- If Stephen was your patient, and palliative care was not called in at the time of his diagnosis, what prevented that consult from happening?
- As a "generalist/primary" palliative care nurse, what do you see as your role in this case?

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Structures and Processes of Care—How To Embed it Into Stephen's Care

- Interdisciplinary planning and care?
- Has Stephen and his families' preferences, values, goals, and needs been identified/expressed?
- Has child life specialists seen Stephen? What about other disciplines?
- Do you have trained and supervised volunteers to assist Stephen and his family?
- Has interdisciplinary team been educated in palliative care?
- Ongoing data focusing on palliative care outcomes?
- Self-care mechanisms for emotional support for staff?
- Community resources available to ensure continuity of quality palliative care across the care continuum?

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A Final Thought…

What is one "action item" you can begin working on when you return to your area of work in an effort to improve palliative care access to your cancer patients and their families?

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Conclusion

- Oncology RNs and APRNs Play A Vital Role in Meeting These Critical Needs
- Fewer oncologists and limited supply of palliative care specialists
- Cancer rates are increasing, as the US population increases
- Survival rates are increasing

ACS, 2017; ASCO, 2017

The Oncology APRN /RN's play a critical role in providing this complex care.

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THANK YOU

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QUESTION:
When should palliative care begin?

ANSWER:
Palliative care is given throughout a patient's experience with cancer. It should begin at diagnosis and continue through treatment, follow-up care, and the end of life".

RATIONALE: Palliative care interventions **early** in the follow-up of unrelieved symptoms in cancer **survivors will improve the quality of life of these patients.**

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