Advanced Oncology Certified Nurse Practitioner

REVIEW COURSE 2024

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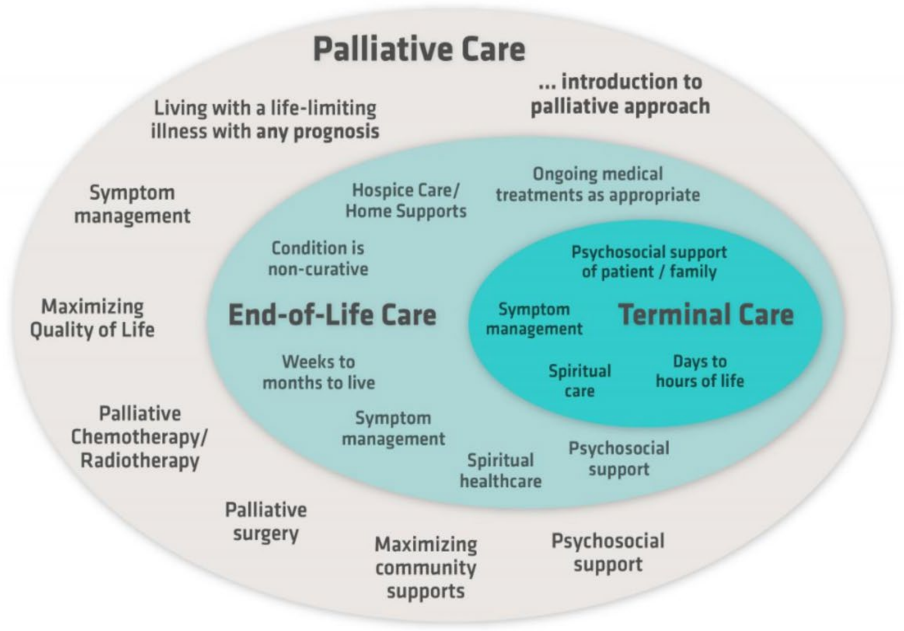
THE UNIVERSITY OF TEXAS
MD Anderson ~~Cancer~~ Center
Making Cancer History®

Palliative Care, Hospice, & End-of-Life Care Overview

- Requires an interprofessional team
- Components: symptom management, family and caregiver support, grief and bereavement, and beyond.
- Palliative, Hospice, and End-of-Life Care:
    - Palliative Care: Interprofessional management of symptoms and support for serious illness.
        - All phases of illness, including curative stages.
    - Hospice Care: Care for terminally ill patients in their last six months of life.
        - Focuses on palliative care by professionals with hospice experience.
    - End-of-Life Care: Care during the last weeks, days, or hours of life.
        - Delivered in various settings (e.g., home, inpatient), often with palliative or hospice support.



Palliative Care

- Palliative care is an “approach to patient, family, and caregiver-centered health care that focuses on optimal management of distressing symptoms while incorporating psychosocial and spiritual care according to patient, family, and caregiver needs, values, beliefs, and cultures” (NCCN, 2023, p. PAL-1).
- The goal is to anticipate, prevent, and reduce suffering, promote adaptive coping, and support the best possible quality of life for patients, families, and caregivers, regardless of the stage of disease or the need for other therapies.

www.nccn.org/professionals/physician_gls/pdf/palliative.pdf

Importance of Palliative Care in Advance Cancer

- Key focus
    - Physical aspects
    - Psychosocial and spiritual support
    - Caregiver involvement
- Integrating palliative care with treatment improves
    - Quality of life
    - Symptom management
    - Advance care planning
    - Survival rates
- Integrated into standard oncology care for all patients with advanced cancer within **eight weeks** of diagnosis and provided alongside cancer treatments (Sanders et al., 2024.)

Eight Domains of NCP Palliative Care Guidelines

1. **Structure & Processes of Care:** Interdisciplinary team structure, care coordination, and sustainability principles.
2. **Physical Aspects of Care:** Holistic, patient-directed symptom management, evidence-based tools for quality of life.
3. **Psychological & Psychiatric Aspects:** Assessment of mental health needs, grief, and bereavement support.
4. **Social Aspects of Care:** Assessment of social supports and safety, role of social workers.
5. **Spiritual, Religious, & Existential Aspects:** Screening for spiritual needs, spiritual care training for clinicians.
6. **Cultural Aspects of Care:** Cultural assessment, cultural humility, family role in care decisions.
7. **Care of Patient Nearing End of Life:** End-of-life symptoms, access to bereavement services.
8. **Ethical & Legal Aspects of Care:** Advance care planning, surrogate decision-making, patient autonomy.

National Consensus Guidelines for Palliative Care. (2018).Clinical Practice Guidelines 4th ed

Key Guidelines for Palliative Care in Cancer

- Patient- and Family-Centered Care
- Continuity Across Health Settings
- Early palliative care introduction at diagnosis of severe illness or advanced cancer
- Interprofessional Team Involvement
- Clinical & Communication Expertise within the team
- Relief of Physical, Emotional, Psychological, and Spiritual Suffering for patients and caregivers
- Focus on Quality of Care
- Equitable Access to palliative care services

Incorporating Guidelines into APN Practice

- **Primary Palliative Care**: Routine assessments with standardized tools.
- **Secondary Palliative Care**: In-depth physical, psychological, social, spiritual, and cultural assessments in home or hospice settings.
- **Tertiary Palliative Care**: Manage complex symptoms with individualized pain assessment and holistic approach to suffering.

Palliative Care Settings

Inpatient Palliative Care

- Specialized hospital care for complex palliative needs
- Predominant model in tertiary and quaternary hospitals
- Focused on acute symptom management and end-of-life decision-making
- Joint Commission Certified in Palliative Care
- Team includes interdisciplinary palliative care experts
- Prioritizes patient and family involvement
- Ensures coordination and communication across healthcare settings

Ambulatory, Home-Based, and Long-Term Care

Ambulatory Models:

- Separate palliative and oncology clinics
- Co-located palliative care clinic
- Embedded palliative care in oncology

Telehealth Palliative Care: Expands access to palliative care services remotely

Home-Based Palliative Care: Supports patients who Continue disease-modifying treatments, decline hospice despite being near the end of life, reside in areas with limited hospice options

Community Resources: Provides alternatives when palliative or hospice care is not chosen

Measuring Outcomes in Palliative Care

- APNs must understand how to measure the outcomes and impacts of palliative care integration.
- **Center to Advance Palliative Care** provides toolkits and metrics for measuring:
  - Structure and process, Operations, and Quality and financial outcomes
- **Key Quality Measurement Tools:**
  - **National Quality Forum**: Measures structure, process, and outcomes in palliative care (physical, psychological, social, cultural, spiritual, and ethical aspects).
  - **CMS Hospice Quality Reporting Program**:
    - Hospice Item Set (measures endorsed by NQF) and CAHPS® hospice survey: Measures patient and family experiences in hospice care.
- **Measuring What Matters Project (MWM)**
  - The American Academy of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA) have outlined ten key indicators to assess physical, psychological, social, spiritual, and program metrics.

Measuring Outcomes in Palliative Care

- **Patient and Family Satisfaction**
  - **CAHPS hospice survey** focuses on end-of-life care satisfaction.
  - **Palliative Care Measures Project** is testing two new measures:
    - Feeling heard and understood (team communication)
    - Receiving desired help for pain (symptom management)
- **Standardizing Metrics for Consistency**
  - Defining and describing palliative care metrics ensures standardization.
  - Consistent metrics are critical for research comparisons and benchmarking.
  - **CMS guidelines** help measure outcomes such as late referral to palliative care.

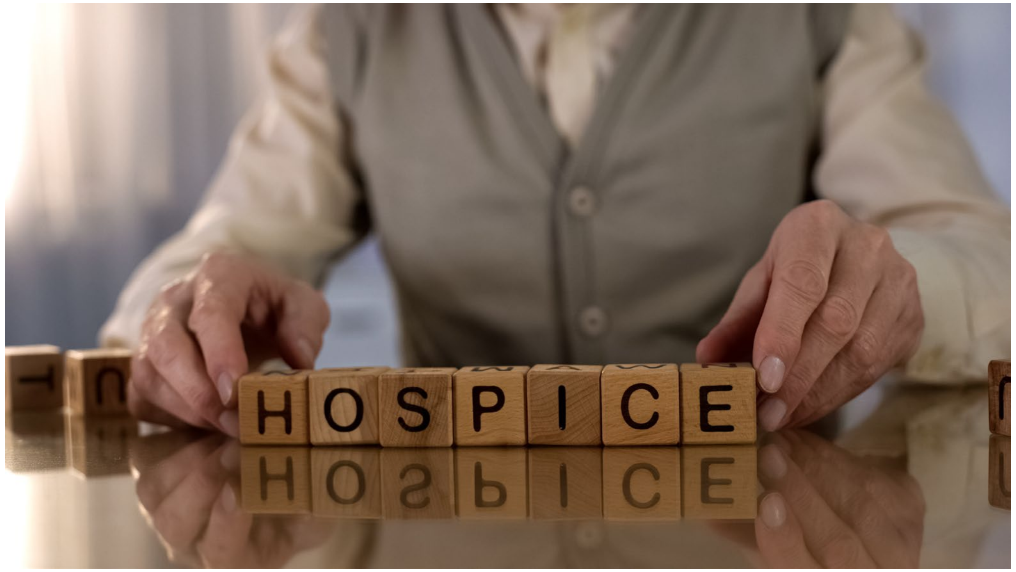
Palliative Care Resources

- **APNs should collaborate with social workers and discharge planners** to address patient and caregiver needs.
- Resource list available for support outside interprofessional palliative care programs
  - Ex: Get Palliative Care, Center to Advance Palliative Care, American Academy of Hospice and Palliative Medicine
- **Growth of Palliative Care Programs**
  - Palliative care programs have doubled in U.S. hospitals over the past decade.
  - Over 80% of U.S. hospitals now offer access to palliative care services.
  - The **Joint Commission** offers certification for palliative care programs, ensuring standards of care.

AOCNP

Hospice Care Overview:

- **Origins:** Founded by Dame Cicely Saunders in the 1960s, based on the concept of "total pain."
- **Interprofessional Team:** Involves nursing, medical, social work, and chaplaincy support.
- **Key Figures:** Dr. Florence Wald helped bring hospice care to the U.S.
- **Care Options:**
  - **Home Hospice:** Enables patients to stay at home, primarily cared for by family and friends.
  - **Inpatient Hospice:** Best for patients with high symptom needs, requiring interventions like IV pain management or complex wound care.



End-of-Life Care Settings (cont.)

- **Home-Based Palliative Care:** Supports seriously ill patients who are:
  - Pursuing disease-modifying treatments
  - Near end of life but decline hospice
  - In areas with limited hospice options
- **Intensive Palliative Care Unit:** Hospital-based care for complex needs
- **Community Resources:** Alternatives when palliative or hospice care are not utilized

Patient Assessment

- Comprehensive Assessment:
  - Complete history & physical examination
    - Evaluate patient condition and predict end-of-life symptoms
    - Formulate differential diagnoses to guide treatment options
- Aligning Treatment with Patient Goals:
  - Consider patient’s priorities (e.g., staying alert vs. sedation)
  - Balance symptom management with quality of life
- Understanding Medication Side Effects:
  - Help patients and families make informed decisions
  - Discussion regarding which symptoms are reversible, and which are not (e.g., Cheyne-Stokes breathing)
- Ongoing Reassessment:
  - Regular evaluation of symptom management interventions
  - Adjust medications and support based on evolving condition
- Support for Caregivers: Frequent education and compassionate communication.

Pain at the End of Life

- Definition: "An unpleasant sensory and emotional experience associated with or resembling that associated with actual or potential tissue damage." (IASP, 2020)
- Assessment Challenges: Communication barriers near the end-of-life complicate pain assessment and management.
- Nonverbal Pain Indicators: Crying, facial grimacing, restlessness, irritability, guarding, groaning, moaning, respiratory distress.
- Common Causes:
  - Decreased Mobility: Skin tears, pressure ulcers, infections
  - GI Cancers: Ileus, obstruction, ascites
  - Leukemia: Hyperleukocytosis
  - Treatment-Related Pain: Neuropathy, mucositis
- Types of Pain:
  - Nociceptive: Tissue injury; intact nerve transmission
  - Somatic: Bones, joints, muscles (aching, stabbing, throbbing)
  - Visceral: Internal organs, smooth muscle (gnawing, cramping, colicky)
  - Neuropathic: Nerve damage

Pain: Treatment

WHO Pain Management Ladder Step

- Step 1: Mild Pain – OTC meds (Tylenol, NSAIDs)
- Step 2: Moderate Pain – Step 1 + opioids
- Step 3: Severe Pain – Step 2 + methadone, IV opioids
- Step 4: Interventional Pain Techniques (nerve blocks, spinal cord stimulators)

Additional Considerations:

  - Administration Route & Organ Function: Adjust for renal and hepatic function
  - Opioid Use: Consider scheduled or long-acting options
  - Steroids: Dexamethasone preferred for potency and minimal mineralocorticoid effects

- **Neuropathic Pain:**
  - Symptoms: Numbness, burning, tingling (often from chemotherapy)
  - First-Line Treatments: Anticonvulsants (gabapentin, pregabalin), SNRIs (duloxetine, venlafaxine)
  - Opioids: For immediate relief while titrating other meds
- **Non-Pharmacologic Options**: Physical therapy, CBT, heat/cold therapy, acupuncture, music therapy, massage, hypnosis

Dyspnea: The Subjective Experience of Breathing Discomfort

- Influences: Physiological, psychological, social, and environmental factors
- Distinction: Dyspnea ≠ Tachypnea, respiratory distress, or hypoxemia, but may be indicated by these symptoms
- Causes:
  - End-of-life factors (fever, acidosis)
  - Lung disease, anemia, deconditioning
  - Cancer-related (pleural effusions, pulmonary edema, ascites, tumor burden)
- Treatment Approaches:
  - Non-Pharmacologic
  - Pharmacologic

Delirium in End-of-Life Care

- Definition: Rapid disturbance in attention and awareness, often fluctuating with cognitive and emotional symptoms
- Types: Hyperactive, hypoactive, or mixed
- Causes: Medication side effects, intoxication, extended hospitalization, or other medical conditions
- Assessment: Essential to rule out other causes and assess reversibility; *Terminal delirium is identified postmortem
    - Tool: Confusion Assessment Method Severity Short Form (CAM s-SF)
- Treatment: Best managed with a multifaceted approach

Nausea & Vomiting in Palliative Care

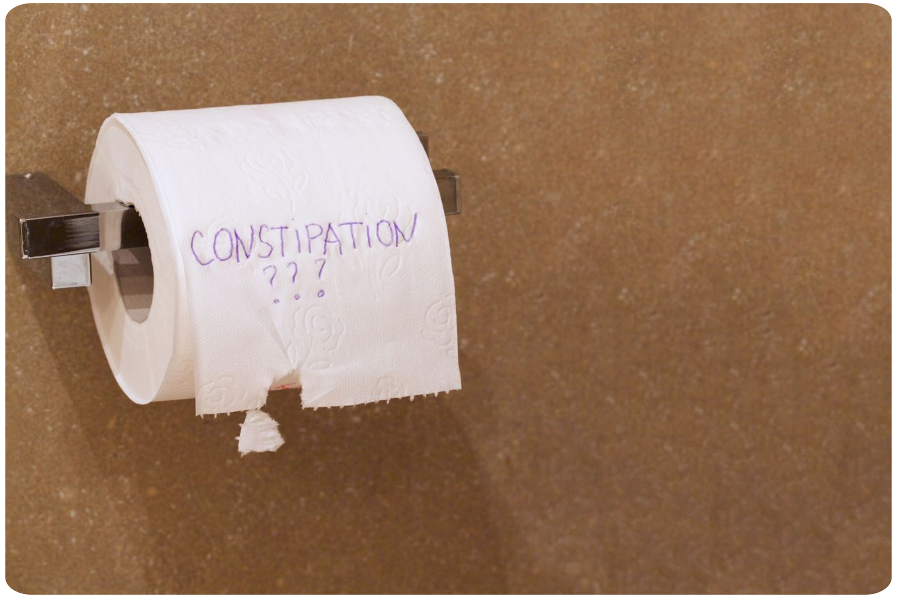
- Impact: Significantly reduces quality of life
- Types: Acute, delayed, or anticipatory
- Causes: Constipation, obstruction, gastroparesis, dyspepsia, tumor burden, neuro malignancies (↑ICP), chemotherapy, opioids
- Treatment Approaches:
  - Non-Pharmacologic: Remove triggers (e.g., perfumes), acupuncture
  - Pharmacologic: Select medication based on cause and nausea pathway
- First-Line Medications:
  - Serotonin antagonists (ondansetron)
  - Anticholinergics
  - Olanzapine (5 mg for advanced cancer)
  - Steroids
  - Cannabinoids (dronabinol, medical cannabis)Benzodiazepines (lorazepam)

Anorexia, Cachexia, and Feeding Challenges

- Weight Loss: Often a sign of nearing end of life
- Anorexia: Loss of appetite or reduced food intake, common in the dying process
- Cachexia: Rapid loss of muscle mass (with or without fat loss), linked to high cytokine and inflammation levels
    - Diagnosis: 5% body weight loss in 6 months without starvation, or BMI < 20 kg/m² with 2% unintended weight loss
- Types: Primary vs. Secondary Cachexia
- Treatment Considerations:
    - Limited benefits from medications, especially with short prognosis
    - Focus on support and education for loved ones

Constipation

- Contributors: poor oral intake, decreased mobility, obstruction, metabolic changes (ex, hypercalcemia), and medication side effects.
- The small bowel and colon should produce stool output despite poor oral intake
- Treatment: Benefits and the burdens of symptom management should be considered



Xerostomia (Dry Mouth)

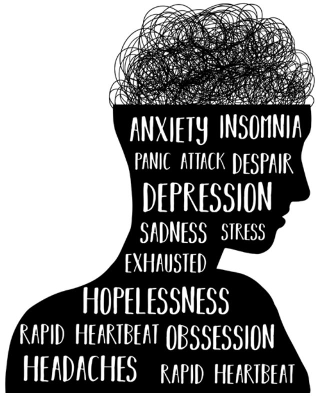
- Impact on Quality of Life: Affects speaking, swallowing, causes oral ulcers, dental issues, and pain.
- Causes: Dehydration, infections (e.g., oral candidiasis), poor oral intake, medications (opioids, anticholinergics), and treatments (chemo, radiation)
- Treatment Approaches:
  - Oral Care: Regular hygiene, humidifier use, emollients (e.g., Vaseline)
  - Saliva Stimulation: Sugar-free gum or hard candy
  - Saliva Substitutes: Use before speaking with loved ones or before bed
  - Toothpaste Caution: Avoid sodium lauryl sulfate

Fatigue

- Multifactorial: underlying disease, physical debility, metabolic abnormalities, and other physical/psychological factors (ex: estate planning)
- Treatment:
  - Educate family that fatigue and increased time sleeping is expected near end of life
  - Focus on energy management
  - Massage, aromatherapy

Anxiety and Depression at End-of-Life

- Common Causes of Anxiety:
    - Existential distress (fear of death, leaving loved ones)
    - Physical symptoms (pain, dyspnea)
    - Medications (e.g., stimulants)
- End-of-Life Considerations:
    - Often overlaps with agitation and terminal delirium
    - Can worsen with changing symptoms or communication barriers
- Depression Symptoms:
    - Low mood, loss of interest, sleep changes, feelings of hopelessness
- Overlap of Anxiety and Depression:
    - Can be acute or chronic, may coincide with other psychiatric conditions
- ASCO Recommendations:
    - Treatment: Interprofessional support in a safe, nonjudgmental environment (chaplains, social workers, therapists)
    - Sources of Anxiety: Fear of the unknown, concerns about dying, existential questions
    - Medications



Seizure Management at End-of Life

- Risk Factors: Higher risk with brain-involved cancers or neurological conditions (e.g., epilepsy)
- Effective Management: Requires proactive planning, education, and readily available antiepileptic medications
- Family and Caregiver Guidance:
  - Stay calm and note seizure duration
  - Contact hospice or medical provider
  - Do not place objects in the mouth or restrain the patient
- Pharmacologic Approach:
  - Ongoing Therapy: Continue antiepileptics for recurrent seizures
  - Administration Options: IV, rectal, or intranasal if oral is not possible
  - Emergency Medications: Use IV or rectal benzodiazepines

Body Temperature Changes

- Common at the end of life
- Common causes: infection, metabolic abnormalities, or common hypoperfused states as the body goes through the normal dying process.
- Education and involvement of caregivers is key
- Warming interventions: blankets, adjustment of room temperature, heating pads (with caution)
- Cooling interventions: cool compresses, intake of cool fluids, adjustment of room temperature
- Fever: antipyretics, antibiotics (case dependent)

Bleeding Events at End of Life

- **Impact on Caregivers:** Can be distressing; preparation and follow-up support are essential
- **High-Risk Patients:** Those with fungating tumors, thrombocytopenia, or head and neck cancers
- **Caregiver Preparation:** Educate on what to expect and how to respond
- **Crisis Medications:** Benzodiazepines and opioids may help but are often limited due to rapid onset
- **Primary Support:** Providing comfort and presence is often the most effective response

Palliative Sedation

- Purpose: Induces minimal consciousness to relieve severe, unmanageable symptoms
- Indications: Reserved for symptoms unresponsive to multiple treatments
- Medications: Commonly used agents include benzodiazepines, barbiturates, and neuroleptics
- Research Insight: Delirium in terminal stages is the most frequent reason for palliative sedation

Family and Caregiver Support

- Family meetings
    - Compassionate communication and active listening
    - Offer knowledge of the disease process, expected prognosis, and treatment options to aid decision-making
    - SPIKES: A communication tool designed to aid in delivering bad news
    - Include: patient, surrogate decision-makers, as well as interprofessional and interdepartmental team members

Approach to Prognosis Discussion

- Keys: Preparation, curiosity, and individualized assessment
- Goal: Help patients form realistic expectations about life expectancy
- Challenges: Clinicians often rely on experience rather than validated (and often unreliable) tools; oncologists may overestimate prognosis
- Considerations:
  - Address emotions underlying prognosis questions
  - Patients/caregivers may choose not to receive prognosis information
  - If caregivers resist sharing prognosis with the patient, prioritize patient rights while understanding caregiver concerns
- **Remember:** Prognosis is an **estimate**

Educating Families on the Dying Process

- Early Education: Regularly inform families about signs of the dying process to reduce distress
- Signs of Approaching Death:
  - Early (within 3 days): Reduced consciousness, decreased activity, difficulty swallowing
  - Later Signs: Loss of radial pulse, jaw movement during breathing, no urine output, peripheral cyanosis, apnea, Cheyne-Stokes breathing, “death rattle” (oral secretions)
  - Additional Late Signs: Nonreactive pupils, unresponsiveness, eyelids not closing, facial drooping, neck hyperextension, grunting, upper GI bleeding
- Last Days to Weeks: Increased time in bed, weakness, decreased interest in food/drink, social withdrawal, confusion, restlessness, hallucinations, discussing “taking a trip”—avoid correcting them
- Vital Signs: Can provide insights but may cause distress; they don’t alter the course of care

Additional Considerations at End of Life

- **Spiritual and Religious Practices**
  - Patients' and families' spiritual/religious beliefs influence healthcare decisions.
  - Some cultures may avoid discussing a terminal prognosis to prevent emotional distress.
  - Euthanasia and hastening death may be against religious doctrines (e.g., Christian Science, Hinduism, Islam).
- **Cultural Sensitives**
  - Cultural beliefs about death differ; e.g., discussing death in Taiwanese culture may be seen as bad luck.
- **Supporting Children and Families**
  - Consider children's age, coping ability, and understanding.
  - Child life specialists can assist families in discussing death and provide resources for ongoing support.
- **Organ Donation**
  - Organ donation options may be limited after chemotherapy, but corneal donation may still be possible, depending on the patient and family’s goals.
  - Advance care planning documentation can help outline donation preferences

Grief and Bereavement

- **Understanding grief in cancer**
  - Patients with advanced cancer face multiple losses (body image, social roles, control, life).
  - Grief is a natural response to these losses, varying in intensity based on significance.
  - Oncology APNs support normal grieving and identify complicated grief needing further care.
- **Types of grief**
  - **Prolonged grief**: Persistent grief lasting over 6–12 months, recognized as a mental disorder.
  - **Disenfranchised grief**: Grief from losses that can't be openly acknowledged (e.g., unsanctioned relationships, miscarriage).
- **Manifestations of Grief**
  - Grief manifests socially, physically, and emotionally.
  - Influenced by religious practices, relationship to the deceased, age, and manner of death.
- **Grief Theories**
  - **Kubler-Ross (1969):** Five stages of grief (denial, anger, bargaining, depression, acceptance).
  - **Worden (2009):** Four tasks of grief (accept loss, experience pain, adjust to new life, and form a new relationship with memories).
  - **Dual Process Model (1999)**: Balances loss-oriented (e.g., yearning) and restoration-oriented (e.g., mastering new tasks) coping.
- **Discussing Death**
  - Avoidance of death discussion can lead to anxiety and depression.
  - Encourage open conversations about feelings and relationships to ease guilt and emotional strain.
  - “Five Things” for Relationship Completion
    - Byock (1997): Patients can find peace by completing these five tasks—seek and offer forgiveness, thank others, express love, and say goodbye.
- **Mourning Practices**
  - Cultural and religious rituals are key to processing grief. Clinicians should support meaningful practices for patients and families.
- **Grief Support**
  - Grief support groups and individual counseling can provide emotional outlets and help find meaning.
  - APNs can offer bereavement follow-up to assess the need for additional services.

Financial and Legal Issues: Advance Care Planning

- **Advance Care Planning (ACP) overview**
  - Identifies and aligns care with a patient's goals and values.
  - This involves discussing treatment preferences documented in advance directives (e.g., healthcare proxy, and living will).
- **Advance Directives**
  - Legal documents outline patients’ care preferences when they cannot speak for themselves.
  - Include healthcare proxies, living wills, and durable powers of attorney.
  - State-specific laws govern advance directives, which may not be valid across state lines.
- **Healthcare Proxy**
  - Designates a surrogate decision-maker for medical decisions when the patient is incapacitated.
  - Includes space for preferences like care and organ donation.
  - Must be signed by two witnesses who are not the named proxy.
- **Living Will**
  - Details healthcare preferences if the patient loses capacity, including pain management, funeral arrangements, and organ donation.
- **Durable Power of Attorney**
  - Authorizes another individual to handle financial and legal matters (e.g., bank transactions, and bill payments) if the patient is incapacitated.
  - Ends when its purpose is fulfilled or at the patient’s death.
  - Must be notarized but does not authorize medical decision-making.

Resuscitation Preferences

- **DNR/DNI Orders**
  - Patients may opt for Do-Not-Resuscitate (DNR) or Do-Not-Intubate (DNI) orders to avoid CPR or mechanical ventilation.
  - Allow Natural Death (AND) is a similar order.
  - Advance directives alone are insufficient; DNR/DNI must be documented in the medical record with a provider order.
- **Institutional and State-Specific Requirements**
  - Clinicians must understand institutional processes for documenting code status.
  - Some states differentiate code status documents for inpatient and outpatient settings, so proper documentation is crucial at discharge.
  - Texas H.B. 3162
- **POLST/MOLST Forms**
  - Physician Orders for Life-Sustaining Treatment (POLST) or Medical Orders for Life-Sustaining Treatment (MOLST) act as portable advance directives.
  - Relevant for chronic illnesses or nursing homes/rehab patients.
  - Often printed on brightly colored paper for easy identification.
- **Additional Legal considerations**
  - End-of-life planning includes discussing property, passwords, and social media accounts.
  - Ensure that the durable power of attorney and healthcare proxy are inactive after death.
  - Next of kin handles body and funeral decisions; custody must be arranged for children under 18.

DNR

DO NOT RESUSCITATE

request limited emerg

record number)

heart stops beating or if I

functioning will be i

Patient and Family Education

- **Support and Education at End-of-Life**
  - Ongoing education is essential for patients, caregivers, and families during end-of-life care.
  - Shifting from disease-directed treatment to comfort care may be challenging, leading to feelings of abandonment.
  - APNs play a crucial role in ensuring continuity of care and supporting patients during this transition
- **Clarifying Goals and Treatment options**
  - APNs assist with clarifying goals of care and discussing treatment options.
  - Guide transitions to hospice or end-of-life care
- **Symptom management education**
  - Teach patients and families about anticipated physical, psychological, emotional, and spiritual symptoms.
  - Educate on early symptom indicators, prevention, and management using pharmacologic and nonpharmacologic interventions.
- **Care Skills Training**
  - APNs provide education on skills such as medication administration, dressing changes, catheter care, and use of medical equipment.
- **End-of-Life education**
  - Whether or not hospice care is chosen, education includes disease progression, signs of approaching death, symptom management in the final phase, and addressing grief and bereavement.

Implications for Oncology APRNs

- **Ethical responsibilities**
  - Oncology APNs care for patients throughout their disease, including end of life.
  - According to the **American Nurses Association** (2015), nurses must respect the dignity and rights of all patients, regardless of illness or proximity to death.
- **End-of-life Care**
  - APNs provide essential symptom management and psychosocial support for patients and families at the end of life.
  - Involve consulting teams like palliative care when needed for specialty management.
- **Upstream perspective**
  - Oncology APNs should support patients early in their disease trajectory, addressing needs before they arise.
  - Early discussions on goals of care, value mapping, and advance directives aid surrogates in decision-making if patients become incapacitated.
- **Advocacy and Relationship-base care**
  - Oncology APNs play a unique role in delivering relationship-based care.
  - Help patients navigate cancer treatment, advocate for themselves, and support them through advanced disease and end-of-life stages.

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Thank you!

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