Disclosures
The presenters have no real or perceived conflicts of interest that relate to this presentation.

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Professionalism
This module focuses on professional practice. It includes a review of ethical principles and how they apply to common practice issues in palliative care such as palliative sedation, assisted suicide/hastening death and the withholding/withdrawing of life-sustaining therapies. Included is an overview of the scope and standards of advanced practice nursing, palliative nursing, self-care, and leadership.
Objectives

1. Discuss how to integrate communication principles and professionalism into practice
2. Describe the application of ethical principles

Professionalism

A. 9% of examination content
   • Approximately 16 questions

B. Content focus
   1. Ethics Principles
      A. Autonomy, beneficence, non-maleficence, veracity, justice, confidentiality
   2. Scope, standards, and guidelines
      A. American Nurses Association – Nursing Scope of Standards and Ethics
      B. Hospice and Palliative Nurses Association – Palliative Nursing Scope and Standards
      C. National Hospice and Palliative Care Organization’s Standards of Hospice Care

Professionalism

2. Scope, standards, and guidelines (continued)
   D. Guidelines from American Pain Society, National Consensus Project for Quality Palliative Care, and other professional organizations
   E. Roles of APRN – clinician, educator, consultant, researcher, and leader

3. Self care and support

4. Leadership and self development
Scope, Standards, and Guidelines

• Set boundaries of practice – usually NP, CNS in hospice and palliative care settings
• Delineate area of foci for graduate education
• Clarify professional scope of nursing practice and specialty scope of practice


Scope, Standards, and Guidelines

Definition of APRN
• Federal definition
• State definition
Definition: Advanced Practice Registered Nurse

A nurse who has earned a graduate level degree in nursing from an accredited program, and is prepared to provide a range of activities including: direct patient care that involves independent judgment, synthesis of complex assessment data, initiation of care plan and treatment regimens, and evaluation of health care environments. Practice requires regulatory recognition beyond the registered nurse license granted by the state Board of Nursing.

National Council of State Boards of Nursing, 2008 Consensus Model.

Definition: Hospice and Palliative Care

Hospice and palliative care is the provision of care for the patient with serious illness and their family with the emphasis on their physical, psychosocial, emotional and spiritual needs. This is accomplished in collaboration with an interdisciplinary team in diverse settings including inpatient, home, or residential hospice; acute care hospitals or palliative care units; long-term care facilities; rehabilitation facilities; home; ambulatory or outpatient palliative care primary care or specialty clinics; veterans’ facilities; correctional facilities; homeless shelters; and mental health settings.

Hospice and Palliative Credentialing Center, 2015

Definition: Hospice and Palliative Care

Hospice and palliative interdisciplinary team members serve in a variety of roles including expert clinicians, educators, researchers, administrators, consultants, case managers, program developers/coordinators, and/or policymakers. Moreover, hospice and palliative care includes holistic assessment of the patient and family, offering information to allow more informed decision-making, meticulous pain and symptom management, determination and optimization of functional status, and support and coping patterns.

Hospice and Palliative Credentialing Center, 2015
HPNA Position Statement

Value of the Advanced Practice Nurse in Palliative Care

“...APRNs are uniquely qualified and positioned to address the myriad needs of individuals facing life-threatening, progressive illness.”

“APRNs who have specialty preparation in palliative care through education and/or clinical practice function as palliative care experts in the clinical nurse specialist or nurse practitioner roles.”

“Palliative APRNs are able to model optimal patient care to all members of the interdisciplinary healthcare team...”

Specific Supporting Documents for APRN Practice

- Palliative Nursing: Scope and Standards of Practice – An Essential Resource for Hospice and Palliative Nurses
- Competencies for the Hospice and Palliative Advanced Practice Nurse
- Advanced Certification in Hospice and Palliative Nursing

Question # 40

Sally Stone, CNS, is working with her hospital in Nebraska to create a job description and guidelines for her practice. Her institution credentialing specialist asks her to verify national recognition of her specialty palliative nursing practice. What document should Sally offer:

A. Her Nebraska state advanced practice nursing act
B. Palliative Nursing: Scope and Standards
C. A collaborative agreement with her physician
D. Her certification in advanced practice hospice and palliative nursing

Resources
Hospice and Palliative Credentialing Center (HPCC)
HPNA Core Curriculum for the Advanced Practice Hospice and Palliative Registered Nurse
Chapter 1 – Evolution of the Advanced Practice Nurse in Palliative Care
Chapter 3 – Promoting Quality Palliative Care

Ethics

ANA Code of Ethics for Nurses

• The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person.
• The nurse respects the patient’s right to self-determination. Nurses assist patients with decisions about resuscitation status, withholding and withdrawing life-sustaining therapies, forgoing nutrition and hydration, palliative care, and advanced directives.
• The nurse should provide interventions to relieve pain and symptoms in the dying patient with respect to evidence-based palliative care.

ANA 2015, p.8
Nursing Aims
The American Nurses Association (ANA) states:

The aims of nursing actions are to protect, promote and optimize health; prevent illness and injury; alleviate suffering.


Goal of Hospice and Palliative Nursing
The goal of hospice and palliative nursing “is to promote and improve the patient’s quality of life through relief of suffering along the course of the illness.”

Hospice and Palliative Nurses Association (ANA & HPNA 2014)

Ethical Principles Important to Palliative Care
Autonomy – The duty to promote and respect an individual’s independent choices in decision making
Beneficence – The duty to do or act in a way that is in the best interest of a patient
Non-maleficence – The duty to do or cause no harm to the patient as well as protect the patient from harm
Confidentiality – The duty to protect the patient’s information
Justice – The duty to promote equal access to care for all people regardless of socioeconomic status, insurance, religion, ethnicity, geography
Veracity – The duty to tell the truth

ANA Code of Ethics 2015
Ethical Process

• It is important to understand the six ethical principles
• Each principle must be weighed separately
• One principle may outweigh another
• Use ethics committees or consultants as needed

Question # 41

Mr. Yaz is a 78-year-old male who has been living independently. He is admitted to the hospital for syncope and is found to have early heart failure and a lung tumor. It is determined that he has decision-making capacity. After discussion of treatment options along with the benefits and burdens of care, Mr. Yaz declines further work up and states he wishes to go home. His family states he is too old to make these decisions and demands he get further diagnostic testing. Which ethical principle should guide the APRN in advocating for Mr. Yaz’s right to make his own healthcare decisions?

A. Justice
B. Veracity
C. Confidentiality
D. Autonomy


Question # 42

Ms. Song is a 56-year-old female admitted for liver disease related to cirrhosis, hepatitis B and C, and HIV. She has had frequent hospitalizations for infections. She has been estranged from her family for several years. Ms. Song has been very clear in her medical visits and has documentation stating that she does not want family informed of her diagnoses. Since she was comatose for several days, a search was made for family. They ask for a family meeting. Which ethical principle will limit the APRN’s ability to discuss the particulars of Ms. Song’s condition?

A. Beneficence
B. Non-maleficence
C. Confidentiality
D. Veracity

Guideline 8.1
The patient or surrogate’s goals, preferences, and choices are respected within the limits of applicable state and federal law, current accepted standards of medical care, and professional standards of practice. Person-centered goals, preferences, and choices form the basis for the plan of care.

Failure to honor the patient's or surrogate's preferences is documented and addressed by the team, and accessible to other health care providers.

To determine decision-making capacity, the ability of the patient and family to secure and accept needed care and to cope with the illness and its consequences is assessed.

Guideline 8.2
The palliative care program identifies, acknowledges, and addresses the complex ethical issues arising in the care of people with serious or life-threatening illness.

Guideline 8.3
The provision of palliative care occurs in accordance with professional, state and federal laws, regulations, and current accepted standards of care.

Guideline 8.1
In the care of pediatric patients with serious or life-threatening illness, the child’s views and preferences for medical care, including assent for treatment (when developmentally appropriate), is documented and given appropriate weight in decision-making.

When the child’s wishes differ from those of the adult decision maker, appropriate professional staff members are available to assist the child as well as the family.
Common Ethical Issues
- Withdrawal or withholding of treatments and technology
- Palliative sedation
- Euthanasia
- Assisted suicide
- Requests for hastened death

Prolongation of Life
- Balancing benefits and burdens
- Curative intent – interventions aimed at ameliorating the disease process
- How long should these interventions be supported?
- Will these interventions change the course of care?
- May they cause more harm and negatively affect quality of life?
- Will their use relegate a patient to a particular setting to die?

Life-Sustaining Treatments (LST)
- Mechanical or invasive ventilatory support (tracheostomy or ET tube)
- Non invasive ventilatory support (BiPAP, CPAP, and high flow oxygen)
- Oxygen via NC
- Cardiac resuscitation by defibrillation
- Vasopressors
- Antibiotics
- Blood products
- Artificial nutrition (TPN, PPN, PEG tubes)
- Artificial hydration (IV fluids)
- Dialysis – all forms peritoneal, hemodialysis and CVVH
- AICD – implanted cardioverters and/or defibrillators
- Cardiac support devices such as LVADs (left ventricular assistive devices)
Life-Sustaining Treatments (LST)

• May in some cases, be very appropriate to relieve physical, psychological, and psychosocial symptoms
• May allow time for the patient and family to prepare and say their good-byes before death, or for a patient to get his/her affairs in order, to complete their emotional and spiritual tasks of dying
• In other cases, such treatments may be seen as prolonging life and suffering of a patient who is dying

Life-Sustaining Treatments (LST)

• May induce secondary problems to the condition they are intended to treat
• May have implications for family members who benefit financially from their family member staying alive (i.e., social security checks, Veteran benefits, etc.)
• May, by the nature of the therapy, limit the patients options for discharge from the hospital

Withdrawal or Withholding of Treatments and Technology

• Ethically and legally the same
• Appropriate when the burdens of care outweigh benefits or cause undue suffering, adversely affect quality of life, or are not in line with goals of care
• Patients have the right to stop treatment, even if it may shorten his/her life
American Nurses Association

American Nurses Association (ANA) defines nursing as "The alleviation of suffering through diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations." Specifically, ANA states, "The APRN assumes responsibility for the safe and efficient implementation of the plan."


End-of-life choices are a quality of life issue. Nurses, individually and collectively, have an obligation to provide comprehensive and compassionate end-of-life care, including the promotion of comfort, relief of pain, and support for patients, families, and their surrogates when a decision has been made to forgo life-sustaining treatments.

ANA Position Statement Registered Nurses’ Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life. 2010.

Euthanasia, Assisted Suicide, and Aid in Dying

The American Nurses Association prohibits nurses’ participation in assisted suicide and euthanasia because these acts are in direct violation of Code of Ethics for Nurses with Interpretive Statements, the ethical traditions and goals of the profession, and its covenant with society. Nurses have an obligation to provide humane, comprehensive, and compassionate care that respects the rights of patients but upholds the standards of the profession in the presence of chronic, debilitating illness and at end-of-life.

ANA Position Statement Euthanasia, Assisted Suicide, and Aid in Dying. 2013.
**HPNA Position Statement on Palliative Sedation**

- Appropriate when it symptoms seem unlikely to respond to further invasive or non-invasive therapies in a timely way without excessive or intolerable side effects/complications
- Consists of monitored use of non-opioid medications to manage intractable symptoms
- Involves putting patient into varying degrees of unconsciousness
- May be planned or urgent, but should be with informed consent

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**Palliative Sedation**

- No agreed upon definition
- The use of medicines to treat an intractable symptom
- The intent is to ameliorate suffering, not to hasten death
- Medications to use include benzodiazepines (midazolam, lorazepam, diazepam), antipsychotics (phenobarbital), or propofol
- Patients can be involved in decision-making
- Many institutions have policies about palliative sedation

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**Medical Futility**

No national consensus on definition

**Concept centers around:**

- Providing treatment with no potential benefit
- No data or evidence to support the treatment or that it should continue
- Promoting a financial burden to the patient/family, and causing physical, psychological, and spiritual suffering

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Euthanasia

• Illegal in the United States
• When one person intentionally ends another person’s life who may have a chronic, progressive, debilitating illness or life-limiting illness
• May or may not be a healthcare provider
• Can be voluntary or involuntary

Assisted Suicide or Physician Assisted Death as defined in the U.S.

• When a physician prescribes medicine to relieve suffering by the intent of hastening death, patient self administers medicine
• Assisted suicide legal only in Oregon, Washington, Montana, Vermont, and New Mexico
• Assisted suicide officially opposed by AMA, ANA, ONS, and HPNA as well as other professional organizations

Question # 43

In a situation where a patient or family is considering stopping treatments; the APRN:

A. Should inform the patient and family when he/she disagrees with the decision and will not write an order
B. Should support the patient and family’s right to decline care and assure their understanding of potential outcomes
C. Should refer to the ethics committee to assure there is precedent for allowing this
D. Only supports the process if there is a policy and procedure to do so

Question #44

A patient with hours to live is writhing in distress from cancer pain and shortness of breath. You write an order for high dose morphine. The nurse asks the difference between starting the infusion and hastening death. What is the best explanation?

A. Palliative care does hasten death, but only if necessary
B. Using medications with the intent to treat pain and symptoms is not hastening death
C. If you change the medication, it is not hastening death
D. This is not hastening death as it is palliative sedation


Additional Reading

Palliative Nursing: Scope and Standards of Practice.
Professionalism (p. 23)
Competencies for the Hospice and Palliative Advanced Practice Nurse, 2nd Edition
Pillars table (p. ix)
Advocacy and Ethics (p. 8)
Professionalism (p. 11)

Additional Reading

Core Curriculum for the Advanced Practice Hospice and Palliative Registered Nurse, 2nd Edition
Chapter 4 – Ethical Issues
Withdrawal of Life Sustaining Therapies
Conversations in Palliative Care: Questions and Answers with the Experts, 3rd Edition
Chapter 16 – Ethics in Palliative Care
Code of Ethics for Nurses with Interpretive Statements
Guide to the Code of Ethics for Nurses
Additional Reading

HPNA Position Statements
Artificial Nutrition and Hydration in Advanced Illness
Palliative Sedation
Role of the Nurse When Hastened Death is Requested
The Ethics of Opiate Use at End of Life
Withholding and/or Withdrawing Life Sustaining Therapies

ANA Position Statement
Registered Nurses’ Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life

Summary

• APRNs must understand the ethical and legal implications of withdrawal and withholding of technology and have policies and procedures for performing this process
• APRNs must understand the ethical and legal implications of the use of palliative sedation for refractory symptoms and have policies and procedures to guide the use of palliative sedation
• APRNs must understand the difference between treatment of pain and symptoms, palliative sedation, hastening death, and euthanasia

Leadership and Self Development
Leadership

Leadership is a standard of professional performance delineated in the HPNA Palliative Nursing: Scope and Standards of Nursing Practice (HPNA 2014)

By the nature of the role, an APRN, “demonstrates leadership in the roles of teacher, clinician, researcher, advocate, mentor, consultant, collaborator, administrator, coordinator, case manager, and leader as appropriate to educational preparation, experience, and position.” (HPNA 2014; ANA and HPNA 2014)

Leadership

Leadership within the nursing profession involves moving the profession forward in the changing landscapes of clinical practice, education, quality, and research

Palliative Nursing Leadership

- Position Statement 2015
- The ability to work with others to transform the care and culture of care delivery for persons with serious illness
- Occurs within clinical care, administration, education, and/or research
- Palliative Nursing Leadership Position Statement 2015
Self Development

- Participating in professional organizations
- Presenting at nursing schools, conferences, governmental meetings, etc.
- Publishing in journals, books, e-print
- Precepting students
- Mentoring colleagues

Question # 45

What would demonstrate an ARPN’s plan for furthering knowledge and expertise in specialty nursing practice?

A. Attending local HPNA educational programs
B. Attending professional union meetings
C. Accruing minimal number of CNEs required for state licensure and national certification as APRN
D. Precepting medical, social work, and psychology students

Self Care
APRN Stress Points

Different assumptions, perspectives and values that may not be articulated, respected, etc. within a team, health care organization, or system
• Lack of role clarity
• Multiple lines of accountability
• Different legal responsibilities
• Budget issues/pressures
• Predictable points of vulnerability

Self Care Necessary

With constant exposure to:
• Death
• Crisis
• Stress
• Negative perception of the specialty

Time Strategies for Self Care

• Ability for control over one’s daily schedule
• Work flow allows for efficient time management
• Time off and away from the work
• Time for new projects
• Time for team meetings for celebrations and difficult times
• Time for education and learning
**Question # 46**

Andrew NP has been a hospice and palliative NP for 10 years. He works on a busy service with 100% of his time focused on clinical care. His case load and acuity is high. He finds he is more tired and irritable lately. What would be appropriate steps to relieve his stress?

A. Talk to his supervisor and tell him he must reduce his case load or he will leave  
B. Evaluate his daily schedule to determine more effective organization and small time out breaks  
C. Meet with the team to discuss methods to support the team  
D. Review his work and determine what causes the most stress

**Additional Reading**

*Conversations in Palliative Care: Questions and Answers with the Experts, 3rd Edition*  
Chapter 35 – Self-Care Strategies

**Summary**

- APRNs must be aware of scope of practice and standards of care related to discipline, professional, federal, and state standards, statutes, and regulations  
- Ethics help guide the APRN in palliative care  
- APRNs must remember leadership is inherent in their role as well as that of change agent  
- Self care is essential in order to assure longevity in the specialty of palliative nursing