End of Life Discussions
OBJECTIVES

1. Describe the difference between Hospice and Palliative Care.
2. Discuss how palliative care is different from acute care.
3. Discuss how nurses support patients and families as they make end-of-life decisions.
4. Demonstrate how to approach benefits and burdens discussions with patients and families.
5. Discuss the importance of presence in end-of-life care.
6. Identify techniques for managing symptoms at end-of-life.
7. Discuss the effect of caregiving on family members.
8. State techniques health care professionals may use to prevent burnout.
- 25% of Americans are not likely to talk about impending death with terminally ill parents.

- Fewer than 25% have put in writing how they want to be cared for at the end of life.

- 20% admit they have not thought about how they want to be cared for at the end of life.

- 15% have thought about their end-of-life care, but have not expressed their preferences.”
The French think death is inevitable.
The British think it’s imminent.
Americans think it’s optional.

Health Care Goals: Trajectory of Cure & Palliative Care

- Talking about end of life is not easy in America.
- The culture *denies death* as much as it *values* independence, achievement, and affiliations.
- Dependence is to be avoided whenever possible.
- As a result of these values and beliefs, Americans tend not to talk about end-of-life care.
Making the Choice

- Abundant technological advances have emerged:
  - Many procedures are available to treat illnesses and thereby extend life.
- The results: Americans live with chronic illness; quality of life years do not dramatically improve.

HUMANS + = IMPROVED LIFE?
Western Culture’s View on Aging and Death

- Sees illness and aging as unproductive, worthless, “might as well be dead”
- “anyone can do anything if he or she tries hard enough”

To view the videos below go to the Module 6 content area

Why are we so afraid of death? - Ira Byock
Why is end of life care ignored by physicians? Ira Byock
World Health Organization
Toolkit for Nursing Excellence at End-of-Life

Transitions

- A **care model** has been proposed by the World Health Organization (WHO). In this model:
  - Disease (cancer, cardiac, pulmonary, hepatic, renal, etc.), treatment, pain relief, and palliative care **all begin at diagnosis and are used concurrently with disease treatments up to death**.

- **Significance**: Attention to the patient’s quality of life is recognized from the time of diagnosis **instead of aggressively attending to symptoms near death**.
Palliative Care and Hospice

- Definition of Palliative Care

  The term is used widely in health care to refer to treatments or interventions (including surgical) that are focused on alleviation of pain or other symptoms, and is not necessarily limited to care provided for eventually fatal conditions.

- Hospice is Palliative Care

  Palliation in relation to end of life care is the relief of symptoms and suffering caused by cancer and other all eventually fatal conditions. Palliation helps a patient feel more comfortable and improves quality of life but does not cure the disease. Palliation of symptoms is a key goal of care for both end of life and palliative care.

Click on the link to view the website then click the browser “Back Arrow” to return to the PowerPoint presentation.
Philosophy of Care

Three Main Components of Hospice

- Home Care
- Inpatient/Acute or Respite Care
- Bereavement

Interdisciplinary Team

- 10% must be Volunteer
- Must prove that the Hospice Solicits for philanthropic support
World Health Organization: Resource Allocation Model

‘Traditional’ model of care for patients with life-limiting illness

- Disease or illness treatment
- Pain relief and palliative care (symptom management)

Hospice last 6 months of life in USA

(Adapted from: WHO, 1990)
World Health Organization: Resource Allocation Model

Proposed model of care for patients with life-limiting illness

(Adapted from: WHO, 1990)
## DIFFERENCES BETWEEN PALLIATIVE CARE AND HOSPICE

<table>
<thead>
<tr>
<th>PALLIATIVE CARE</th>
<th>HOSPICE CARE</th>
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<tbody>
<tr>
<td>An interdisciplinary approach to care that focuses on increasing comfort and quality of life at any time during the span of a life-limiting illness.</td>
<td>A system for delivering palliative care during the last months and weeks of a life-limiting illness.</td>
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<tr>
<td>No time limits to prognosis.</td>
<td>Prognosis defined by Medicare regulations to be approximately 6 months or less.</td>
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<tr>
<td>Provided in Primary, Secondary, Tertiary inpatient settings as well as Community Settings.</td>
<td>Provided in Community Settings primary where the patient resides with temporary movement to inpatient settings when needed for respite or symptom management.</td>
</tr>
<tr>
<td>Reimbursement is provided through traditional insurances coverage with special coding depending on treatment.</td>
<td>Transfer traditional insurance benefits to specialized, capitated hospice benefit.</td>
</tr>
<tr>
<td>Patient usually considered to be in active, life-prolonging treatment and is usually a full code or a DNRCC-Arrest, seldom DNRCC.</td>
<td>Patient usually receiving treatment aimed at comfort, not length of life. Patient usually DNRCC but not a requirement.</td>
</tr>
</tbody>
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Bereavement care provided for surviving Significant others.
To view the video below go to the Module 6 content area

- Hospice Bereavement Care  Camp Hope
The National Consensus Project for Quality Palliative Care (NCP)

Serving as a Task Force of:

[AAHPM]
American Academy of Hospice and Palliative Medicine

[HPNA]
Hospice and Palliative Nurses Association

[Organization]
National Hospice and Palliative Care Organization
The National Consensus Project for Quality Palliative Care (NCP)

“The purpose of the National Consensus Project for Quality Palliative Care is to promote the implementation of Clinical Practice Guidelines that ensure care of consistent and high quality, and that guide the development and structure of new and existing palliative care services.”
Guidelines are based on the following:

**Domains of Quality Palliative Care**

1. **Structure and Processes of Care**
2. **Physical Aspects of Care**
3. **Psychological and Psychiatric Aspects of Care**
4. **Social Aspects of Care**
5. **Spiritual, Religious and Existential Aspects of Care**
6. **Cultural Aspects of Care**
7. **Care of the Imminently Dying Patient**
8. **Ethical and Legal Aspects of Care**
On-going, Continuous Care

- Americans say that the following services are most important for a terminally ill loved one:
  - Someone to ensure that the patient’s desires are honored.
  - Choice among types of services the patient can receive.
  - Pain control tailored to the patient's wishes.
  - Spiritual support for the patient and family.
  - End-of-life care provided without consideration of where the patient is living.
  - Care to be provided in the patient’s home or the home of a family member or loved one.
  - Continuity of caregivers, no matter where the patient is staying.
Awareness of Hospice Services
2001

Research findings indicate that most Americans are completely unaware of hospice services:

- Nearly 80% of Americans do not think of hospice as a choice for end-of-life care.
- 75% do not know that hospice care can be provided at home.
- Fewer than 10% know that hospices provide pain relief for the terminally ill.
- 90% don't know that Medicare pays for hospice.
Clarifying Values & Priorities: Patient, Family, Healthcare Providers

- Health professionals provide active, desirable, and important comfort care to the dying.
- In order to provide quality comfort care to the dying, health professionals elicit, document, display, and assist in implementation of the patient’s wishes for end of life care.
- This comfort care service is not assisted suicide or euthanasia.
American Nurses Association

- ANA position on end-of-life:
  - “Nurses, individually and collectively, have an obligation to provide comprehensive and compassionate end-of-life care which includes the promotion of comfort and the relief of pain, and at times, foregoing life-sustaining treatments.”

Source: ANA Nursing World - Used with permission.
BENEFITS VS. BURDENS DISCUSSIONS
Withholding, Withdrawing and Refusal of Treatment:

Honoring the refusal of treatments that a patient does not desire, that are disproportionately burdensome to the patient, or that will not benefit the patient can be ethically and legally permissible.

Within this context, withholding or withdrawing life-sustaining therapies or risking the hastening of death through treatments aimed at alleviating suffering and/or controlling symptoms are ethically acceptable and do not constitute assisted suicide.

There is no ethical or legal distinction between withholding or withdrawing treatments, though the latter may create more emotional distress for the nurse and others involved.
Life-Sustaining Treatments

- Resuscitation
- Diagnostic tests
- Artificial nutrition and hydration
- Elective intubation
- Surgery
- Antibiotics
- Dialysis
- Other treatments
- Blood transfusions, blood products
- Future hospital or intensive care unit admissions
The provision of medications with the intent to promote comfort and relieve suffering is not to be confused with the administration of medication with the intent to end the patient's life.

"The nurse may provide interventions to relieve symptoms in the dying client even when the interventions entail substantial risks of hastening death."
Clinical policy of care at the end of life and the professional practice it guides should:

- Respect the dignity of both patient and caregivers.
- Be sensitive to and respectful of the patient's and family's wishes.
- Use the most appropriate measures that are consistent with patient choices.
- Encompass alleviation of pain and other physical symptoms.
- Assess and manage psychological, social, and spiritual/religious problems.
- Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers).
Core Principles for End-of-Life Care con’t

- Provide access to any therapy which may realistically be expected to improve the patient's quality of life, including alternative or nontraditional treatments;
- Provide access to palliative care and hospice care;
- Respect the right to refuse treatment;
- Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences;
- Promote clinical and evidence-based research on providing care at the end of life.

Psychosocial Principles

- Aims:
  - Reduce uncertainty
  - Enhance relationships
  - Provide direction for patient and family
- What patients want to know: they will not be abandoned
- A large part of the message is non-verbal
- So bring all communication information from Psych with you to this encounter
“While physical parameters of life contract, the capacity to integrates one’s life experiences may expand.

In the shadow of mortality, individuals may discover that their philosophical values stand in sharp relief to the prior decades of habitual and unexamined living.”

Nelson-Becker, 2006

View these videos by going to the Content area of Module 6

- Why is end of life care ignored by physicians
- How can one die well - Ira Byock Dying Well
- What is the role of Spirituality?
Breaking Bad News

- Telling patient and family together usually recommended.
- False optimism a potent destroyer of hope.
- Use questions to find out what patient wants to know at this moment.
Role of Hope

- Hope is an expectation greater than zero of achieving a goal.
- Setting realistic goals: perhaps several short-term realistic ones.
- Can hope for a peaceful death.
You might hear

- “God is doing this to teach me something—although I don’t know what it is.”
- “I wouldn’t have learned to appreciate my family/life if I hadn’t suffered like I did.”
- Seeing my father die that way was a wakeup call from God telling me to take better care of myself.”
- “What did I do to deserve this?”
- “Why is God punishing me like this?”
- “I am just getting what I deserve.”
Or you might hear

- “This is what I get for not taking care of myself all these years. It was bound to catch up with me.”
- “This is all my fault. I have only myself to blame.”
- “I certainly don’t like all the pain this illness has caused, but it does remind me of Jesus’ suffering; I am sharing in that, and consider it a blessing.”
- “Some good is going to come of all of this, I am not sure what, I just know that it will.”
- “I don’t know why I am suffering. I gave up trying to figure it out. I’m content with simply knowing God is here with me.”
Communication as a vital tool

- The aims of communication:
  - Reduce uncertainty
  - Enhance relationships
  - Provide direction for patient and family
Being Present

- The way we are with others
- Reflects the non-doing, non-knowing aspects
- Centered/mindful
  - Slowing down
  - Being Quiet
  - Non-anxious
  - At peace
Pushing Through

It’s possible I am pushing through solid rock in flint-like layers, as the ore lies, alone; I am such a long way in I see no way through, and no space: everything is close to my face, and everything close to my face is stone.

I don’t have much knowledge yet in grief so this massive darkness makes me small.

You be the master: make yourself fierce, break in: then your great transforming will happen to me, and my great grief cry will happen to you.

Rainer Maria Rilke
Being Present: Making yourself “Fierce”… “Wholehearted”

- Requires:
  - Attentiveness
  - Receptivity
  - Openness
  - Availability
Runaway Bunny

View this video by going to the Content area in Module 6
S-P-I-K-E-S—Six Step Protocol

- **S**—Setting:
  - Ensure that the privacy and comfort of the medical staff and patient/family are maintained. Check that the appropriate people are present when the news is delivered.
  - In some cultures, it is expected that the head of the family be present to make all decisions. “Is there anyone with you today that you would like to have join us?” Allow sufficient time for questions.

from Baile, Buckman, Lenzi, Glober, Beale, & Kudelka, 2000
P—Perception:

- Determine what the patient’s or family’s perception of the illness or symptom is.
- Ask what is known about the illness, symptom, and what the patient/family suspects is occurring. “I’d like to verify with you that we have the same understanding about why you’re here in the hospital . . . Could you tell me . . . .”
I—Invitation:

- Obtain permission from the patient or family for the information. Find out how much the person wants to know “I’d like to answer your question about . . . . Would that be all right?”
Knowledge:

- Provide knowledge and education about the needed concern.
- Warn first about the sharing of unfavorable news. “The news is not what we had hoped for [pause].”
- “Unfortunately, it looks like the tumors have not responded to treatment [pause].”
- “It appears as if they actually have increased in size, which is most likely the reason for her symptoms.”
K—Knowledge cont:

- Try small “chunks” of information, and avoid jargon. Pause and check the response before proceeding to more threatening or unfavorable information.
- Avoid being blunt, (e.g., “you’re going to die”), incomplete information, or false hope.
- Provide education in simple language, and check for understanding.
- Always indicate that there is hope rather than “there’s nothing more we can do.”
E—Emotion:

- Respond to the patient or family’s emotional response with empathy.
- Address patient’s and nurse’s/medical staff’s emotions with empathic responses and gestures (e.g., touching may be very supportive).
- Clarify, explore, and validate the patient’s or family’s feelings or concerns.
S—Summary:

- Review the information to provide a summary strategy.
- Respond to questions.
- Discuss options
- Provide information or referral to medical staff for follow-up.
Practicing Presence

Responding includes:

1. **Understanding**: reflecting back their feeling- assures they have been heard
   
   “it worries you that you should hate your father, and you feel guilty for hating him”

2. **Being Supportive**: help bear the feeling-
   
   Communicate: “I am here, and ready to listen”
Scenarios

View these videos by going to the Content area in Module 6

End of Life Discussion from Oregon Health and Science University

Reflective Discussion Video - Discussing Advanced Illness as Breaking Bad News

Reflective Discussion Video - Talking About End Of Life Care
Practicing Presence

- **Avoid:**
  
  “I know exactly how you feel” or “I understand.”

  “Time heals all wounds.”

  “Wow, how awful!”

- **Say:**
  
  “I can’t imagine what you’re going through.”

  “Can you tell me more about that?”

  “I’m sorry to hear that. I have no idea what that must have been like for you.”
Avoid:  
“This is what always works for me”

Say:  
“I’m not sure how I can help you. What helps you through times like this?”
Some words to use and practicing presence

REMEMBER: Just being there matters more to people than what you say!

- “I can’t imagine what you are going through.”
- “I notice your tears. Can you tell me about them.”
- “Tell me more” or “Say more about that.”
- “I’m sorry to hear that. I have no idea what that must have been like for you.”