Palliative Care, Hospice & Advance Directives

Dr. Valerie Gruss, PhD, APN, CNP-BC
Palliative Care
Learning Objectives

Upon completion of the learning module the learners will be better able to:

- Differentiate between hospice and palliative care
- Identify what palliative care services are available to eligible persons
- Describe the skills to deliver bad news to patients/families
- Explain the palliative care management of common symptoms, such as pain management
What should everyone know about palliative care?
Background
What is Palliative Care?

- Palliative care aims to aggressively **treat symptoms** and **improve quality of life** for patients facing life-limiting illness
- The goal is to improve quality of life for both the client **and** the family
- It provides clients with relief from the symptoms, pain, and stress of a serious illness, whatever the diagnosis
- Care and services are provided by an interdisciplinary team

National Hospice and Palliative Care Organization: http://www.nhpco.org/nhpco-0
Assessment Question #1

True or False?

Palliative care should be used as a means of directing a client into hospice care or because a patient is elderly
Assessment Question #1

True or False?

Palliative care should be used as a means of directing a client into hospice care or because a patient is elderly

FALSE
Palliative Care Services

- Pain and symptom management
- Prognostic Estimates and discussions
- Coping & Spiritual support
- Goals of Care Discussions
- Disposition planning
Who is Eligible?

- It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.
- Provided by a team of doctors, nurses, and other specialists who work collaboratively with other caregivers to provide an extra layer of support.
#1 Barrier to Palliative Care

The misconception that palliative care = hospice
Hospice Care

- Hospice care is used when you can no longer be helped by curative treatment, and you are expected to live about six months or less if the illness runs its usual course.
**Palliative Care Versus Hospice**

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<td><strong>Services Offered</strong></td>
<td></td>
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</tr>
<tr>
<td><strong>Home Palliative Care</strong></td>
<td><strong>Home Hospice</strong></td>
</tr>
<tr>
<td>1-2 RN visits per month</td>
<td>1-3 RN visits/wk, 1-3 CNA visits/wk. PRN visits from MD, SW, chaplain, psychologist</td>
</tr>
<tr>
<td>Hospice agency bills per visit like home physicians.</td>
<td>Hospice agency is paid $145 per day from hospice admission until death.</td>
</tr>
<tr>
<td>Medicare continues to pay for the same level of care</td>
<td>Hospice agency must cover all treatments related to primary hospice diagnosis</td>
</tr>
<tr>
<td>RN available by phone 24-7</td>
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</tr>
<tr>
<td>Bereavement support for 13 months following death</td>
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True or False?

Palliative care services include RN visits and bereavement support
Assessment Question #2

True or False?

Palliative care services include RN visits and bereavement support

TRUE
Simultaneous Model of Care

Therapies to Prolong Life

Palliative Care

Hospice

Bereavement

Death
Where do Americans Die?

Where Americans die:
1. Hospitals- 50%\(^1\)
2. Nursing Homes- 30%\(^1\)
3. Home- 20%\(^1\)

Where people prefer to die:
1. Home (60-80%)\(^2\)
2. Hospitals
Checklist to Identify Patients for End-Of-Life Care

Tool: CriSTAL (Criteria for Screening & Triaging to Appropriate Alternative Care)

• Most likely predictors of death in the short term (30 days) to medium term (12 weeks).
• Checklist of 29 predictors of death, including:
  • Age 65 years or older, plus either emergency admission for the current hospitalization (associated with 25% mortality within 1 year) or two or more deterioration criteria, including change on the Glasgow Coma Score, low systolic blood pressure, slow or rapid respiration, low or high pulse rate, need for oxygen therapy or oxygen saturation less than 90%, hypoglycemia, or repeat or prolonged seizures.
  • Additional risk factors or predictors of short- to medium-term death, including personal history of active disease (advanced malignancy, chronic kidney disease, chronic heart failure, chronic obstructive pulmonary disease, new cerebrovascular disease, myocardial infarction, moderate or severe liver disease, cognitive impairment), as well as previous hospitalization within the last year, or repeat intensive care unit admission at the previous hospitalization.
  • Other factors, such as evidence of frailty, residence in a nursing home or supported-living facility, proteinuria, and abnormal electrocardiogram findings.

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End of Life Trajectories

Source: Murray, S.A. et al

- Cancer (n=5)
- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
Prognosis
Estimating Prognosis

- Oncologists overestimate prognosis in advanced cancer by a factor of 2-5
- Longer estimates when physician knows patient longer
- Longer estimates with less physician experience
- ICU doctors underestimate prognosis (Christakis, 1999)
Communicating Bad News

• Can be learned and mastered
• 6-8 step approaches
• SPIKES
  
  S – Setting up the interview
  P – assess patient’s Perception
  I – obtain the patient’s Invitation
  K – give Knowledge and info to patient
  E – address patient’s Emotions with Empathetic responses
  S – provide patient a Strategy and Summary
Doctrine of Double Effect

- Intention must be good
- Bad effect can be foreseen, but not intended
- Suffering must be severe enough to warrant the risk
- Bad effect cannot be the means to the good effect
Common Misconceptions

- 30-40% of patients getting palliative cancer treatments believe they are being treated with curative intent (Gattellari, 1999) (McKillop, 1988)

- 69-81% of patients with Stage IV lung & colon cancers did not report understanding that chemo was not at all likely to cure their cancer (Weeks, 2012)
Client Autonomy and Informed Decision-Making

- Requires dedicated time from clinicians
- Bringing up prognosis
- Relieve fears of terminal suffering and medical abandonment
End of Life Decisions: The Conversation

The Conversation Project from the Institute for Healthcare Improvement (IHI)

- http://theconversationproject.org/

- The goal of The Conversation Project is to ensure that everyone’s end-of-life wishes are expressed and respected

- Includes step-by-step instructions for how to consider and discuss end of life care issues
Assessment Question #3

True or False?

The goal of The Conversation Project is to ensure that everyone’s end-of-life wishes are expressed and respected.
Assessment Question #3

True or False?

The goal of The Conversation Project is to ensure that everyone’s end-of-life wishes are expressed and respected

TRUE
Pain
Pain Background

- The International Association for the Study of Pain defines pain as an "unpleasant sensory and emotional experience associated with actual or potential tissue damage"

- **Pain affects more Americans than diabetes, cancer, and heart disease combined** *(National Institutes of Health Pain facts)*

- Chronic pain is the most common cause of long-term disability, affecting about 50 million Americans annually *(National Institutes of Health Pain facts)*

Background

Pain Leads To:

- Disability\textsuperscript{2}
- Social isolation\textsuperscript{3}
- Depression\textsuperscript{1,2}
- Falls\textsuperscript{5}
Pain: Approach to the Client

Pain is subjective
► Only the client knows how much pain they are in, and only they can decide how far they want to go for treatment

Pain is both a symptom and a disease
► Eliminate dangerous and progressive diseases!
► Prevent centralization
Pain: Approach to the client

- Establish report with client
- Find the source
- Treat both the primary source and the presenting symptoms
- Screen for non-pain problems
- Restore function
Pain assessment

Common Terms - Pain Scales

Numeric Rating Scale – 0-10 scale

Wong – Baker *Faces Scale* – 0-10 scale
Medications

Special Considerations:
- Common to lose the oral route
- Patches, sublingual and subcutaneous delivery
- Kidney/Liver failure
- Nausea meds

Pharmacology and the Older Adult
- Older adults are at increased risk for adverse drug reactions due to age- and disease-related changes in pharmacokinetics and pharmacodynamics
- Monitor medication effects closely to avoid overmedication or undermedication and to detect adverse effects
- Assess liver and kidney functioning
Management of Pain: Medications (Opioids)

**Opiates:**
- **Mild pain:**
  - codeine containing medications (Tylenol # 3)
- **Mild – to – moderate:**
  - hydrocodone (Hycodan, Vicodin, Vicoprofen, Lortab)
- **Moderate:**
  - oxycodone (Oxycontin, Percocet, Percodan)
- **Severe:**
  - fentanyl transdermal (Duragesic)
  - hydromorphone (Dilaudid)
  - morphine
  - Methadone – requires specific DEA licensing and training

**Side Effects:**
- Nausea and vomiting
- Constipation
- Itching
- Jerky muscular movements
- Sedation
- Confusion
- Respiratory depression

The Role of Opioids

- Mainstay of Treatment for pain and refractory dyspnea
- Underutilized more so in end of life (EOL)
  - Concern for addiction and hastening death
  - These are rarely problems in EOL care
- Large therapeutic window
Non-Pharmacologic Pain Relief

Psychological support:

- Psychological counseling for stress management, cognitive behavioral therapy or biofeedback
- Group counseling for couples or families to decrease interpersonal stress
- Screening for adjustment disorder, depressive disorders
- Management of secondary symptoms such as insomnia
Non-Pharmacologic Pain Relief

Modalities are energy sources that provide pain relief and reduce inflammation:

- Heat
- Ice
- Transcutaneous electrical nerve stimulation (TENS)
- Ultrasound
Referral Cue

*Remember that Physical Medicine (PM & R), Physical Therapists, Occupational Therapists, and Chiropractors are experts in pain management*

- Physical Medicine: Goal: Treat the source, Return normal function
- Physical therapy (such as stretching and strengthening activities) and low-impact exercise (such as walking, swimming or biking) can help reduce the pain. Other therapies include heat and massage
- Occupational therapy teaches how to pace activities and how to do ordinary tasks differently
- Chiropractic Manipulations – massage and manipulation that may give relief of pain.
Non-Pharmacologic Pain Relief

*Referral cue: Complementary and Alternative Medicine (CAM)*

- **Acupuncture** - This ancient Chinese practice uses very thin needles at very specific points on the skin to interfere with nerve impulses. Can be used for both acute and chronic pain.

- **Biofeedback** – Uses visual or sound cues to help people control their response to pain. They can learn to relax muscles and stay calm.

- **Herbal supplements** – are often useful, are often powerful, may interact with other medications, may have adverse effects akin to prescribed medications.
Assessment Question #4

True or False?

The palliative care management of common symptoms, such as pain management, include both pharmacologic (medications) and non-pharmacologic approaches.
Assessment Question #4

True or False?

The palliative care management of common symptoms, such as pain management, include both pharmacologic (medications) and non-pharmacologic approaches

TRUE
When to Consult?

Patients with a terminal condition and:

- Symptoms uncontrolled
- Unrealistic goals
  - Despite primary team broaching prognosis
- Trouble coping
  - And needing multidisciplinary support
- Hospice eligibility unclear to primary team
  - If client qualifies for and agrees to hospice, work with regular social worker directly
Hospice Eligibility

- Life expectancy <6 months
- Not receiving life prolonging therapies like chemotherapy
  - Except when the VA is the payer
- Is DNR status a requirement for hospice?
Summary

Making Sense of the Longer Survival

- Interventions have marginal benefit and real harm
- Added coordination from interdisciplinary team
- Assistance with ADLs
- Psycho-spiritual support

Palliative care prolongs life BUT the main goal is to maximize Quality of Life
Resources

- Palliative Care: The Legal and Regulatory Requirements
- Sample Palliative Care Services Agreement
- Palliative Care Checklist

Found at: http://www.nhpco.org/palliative-care-legal-and-regulatory-resources
Questions?
References and Materials


Hospice and Advance Directives

Dr. Valerie Gruss, PhD, APN, CNP-BC
Learning Objectives

Upon completion of this learning module, learners will be better able to:

- Differentiate between hospice and palliative care
- Discuss what patients qualify for hospice care
- Learn how to deliver bad news using the method suggested in the GRS
- Describe advance directives
BACKGROUND
History/Background: Hospice and Palliative Care

- The word “hospice” was initially used similarly to the way the word “hostel” is used today, as a rest stop or waystation for travelers on long journeys

- **1963**: According to the National Hospice and Palliative Care Organization, Dr. Cicely Saunders first proposes the idea of specialized care for the dying in a speech at Yale

- **1967**: Dr. Saunders establishes the first Hospice, St. Christopher’s Hospice, in the U.K.
History/Background

- **1982**: Medicare begins funding for hospice care
- **1984**: JCAHO initiates hospice accreditation
- **1988**: The American Academy of Hospice and Palliative Physicians is formed
- **1997**: The American Board of Hospice and Palliative Care is incorporated to provide certification for hospice and palliative care
What is Hospice and Palliative Care?

- *Hospice* is the comprehensive care of dying patients

- *Palliative care* is the management of symptoms and quality of life in patients facing life-limiting illnesses
## Background: Differences Between Hospice and Palliative Care

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Assessment Question #1

True or False

Both hospice and palliative care use a team approach and provide psychological and spiritual support to patients and families.
Assessment Question #1

True or False

Both hospice and palliative care use a team approach and provide psychological and spiritual support to patients and families

TRUE
Hospice Care

- 60-80% of patients state that they prefer to die at home, but only 20% of people died at home as of 2004 (50% died in hospitals)
- **To qualify for hospice care**, a patient must have a prognosis of less than 6 months and be willing to forgo curative therapies (note that this does not mean that we forgo all therapies, only those designed to exclusively extend life)
  - There are some cases in which curative intent can be pursued, such as the VA
  - Oncologists statistically overestimate prognosis, while intensivists statistically underestimate prognosis
Assessment Question #2

True or False

To qualify for hospice care, a patient must have a prognosis of less than 6 months and be willing to forgo all therapies including comfort measures.
Assessment Question #2

True or False

To qualify for hospice care, a patient must have a prognosis of less than 6 months and be willing to forgo all therapies including comfort measures

FALSE
End Of Life Decisions: The Conversation

What do people want at end of life?

- 90% of respondents said it was important to discuss end of life care with loved ones, but only 27% have actually done so¹
- 82% of respondents said it was important to put their wishes in writing, but only 23% have actually done it²

¹The Conversation Project Survey, 2013
²CA Healthcare Foundation, 2012
Giving Bad News

The following method comes from the GRS teaching slides on palliative care:

- Prepare
- Establish the patient’s understanding
- Learn how much the patient wants to know
- Deliver the information
- Respond to the patient’s feelings
- Organize a plan and follow-up procedure
End of Life: The Conversation

The Conversation Project from the Institute for Healthcare Improvement (IHI)

http://theconversationproject.org/

The goal of The Conversation Project is to ensure that everyone’s end-of-life wishes are expressed and respected

Includes step-by-step instructions for how to consider and discuss end of life care issues
Assessment Question #3

True or False

The Conversation Project provides step-by-step instructions for how to consider and discuss end of life care issues with clients.
Assessment Question #3

True or False

The Conversation Project provides step-by-step instructions for how to consider and discuss end of life care issues with clients.

TRUE
End of life: The Dying Process

The Dying Process is a social, cultural, and personal experience

‘Dying Process’ includes 4 domains of comfort care at the end of life and non-pharmacologic and pharmacologic approaches to managing symptoms and issues of dying

1. Physical
2. Mental and Emotional Issues
3. Spiritual issues
4. Practical Tasks
Resources

National Hospice and Palliative Care Organizations: http://www.nhpco.org/

**Rural Providers** Hospice Resources:


*Providing Hospice and Palliative Care in Rural and Frontier Areas*, the rural toolkit A project of the National Hospice and Palliative Care Organization, the Center to Advance Palliative Care, and the National Rural Health Association $19.95 on-line publication

**Veterans:** Veterans can receive hospice care through the VA. The VA can purchase hospice services from community providers, including hospice care provided at home or in an institution.

http://www.nhpco.org/billing-and-reimbursement/department-veterans-affairs-va
Advance Directives
Advance Directives

- Durable Power of Attorney for Health Care
- Durable Power of Attorney for Property
- Living Will
- Provider Order for Life-Sustaining Treatment (POLST)
Advance health care directives, are instructions given by individuals specifying what actions should be taken for their health in the event that they are no longer able to make decisions due to illness or incapacity.

A living will is one form of advance directive, leaving instructions for treatment. Another form of authorization is the power of attorney for health care described previously. People may have one or the other or a combination of both.
Powers of attorney (POA) are authorized by the State. **In Illinois,** all powers of attorney are “durable” (by law) unless the document specifically states that the power of attorney is not meant to be durable

- Non-durable powers of attorney are usually done for a specific transaction, like a real estate closing, and do not need to be “durable”. “Durable” powers of attorney continue to be valid even after the principal is incapacitated

A durable power of attorney allows a competent person (the “principal”) to appoint an agent to make decisions for the principal when the principal is incapacitated and unable to make decisions

- This period of incapacity may be caused by a medical situation, such as a coma, or a period of mental incapacity, such as mental illness
Assessment Question #4

True or False

Advance Directives include Power of Attorney, Living Wills and Guardianship?
Assessment Question #4

True or False

Advance Directives include Power of Attorney, Living Wills and Guardianship?

FALSE (Guardianship is not included)
2 Types of Power of Attorney (POA)

**Power of Attorney for Health Care.** The principal delegates power to an agent (trusted friend or family member) for health care and personal care issues decisions.

- This is a document indicating which individual is responsible for making medical decisions and is a legal document. Must be distinguished from a durable PoA, which handles financial matters.
- Patients should be encouraged to name someone who understands their wishes and lives in the same state as they do as their PoA.

**Power of Attorney for Property.** The principal delegates power to an agent for financial and property management issue decisions.

*These two separate documents are powerful tools that can be used to assist and protect an older or disabled person, or be misused to exploit that person*
Power of Attorney: Agents

- The person whom the principal designates as the ‘agent’ must be age 18 or over and cannot be his/her doctor or someone who is paid to provide health care services to the principal.
- The same person may serve as both the health care agent and the financial agent, or different individuals may be appointed.
- The extent of the powers which the principal delegates to the agent may be very broad, or narrow and specific. These are matters at the discretion of the principal.
- The powers the principal gives to the agent, his/her right to revoke those powers and the penalties for violating the law are explained more fully in Section 4-5, 4-6, 4-9, and 4-10(b) of the Illinois “Powers of Attorney for Health Care Law.”
Decision-Maker if No PoA Is Named

1. Court-appointed guardian
2. Spouse
3. Adult children
4. Parent
5. Adult siblings
6. Adult grandchildren
7. Close friend
A living will usually provides specific directives about the course of treatment that is to be followed by health care providers and caregivers. In some cases a living will may forbid the use of various kinds of burdensome medical treatment. The living will is only used if the individual has become unable to give informed consent or refusal (i.e., "individual health care instruction") due to incapacity. A living will can be very specific or very general.

**Living Will:**
- A legal document that describes what steps the patient would desire to have taken if they are unable to make decisions for themselves, usually with regards to resuscitation and advanced life support. In many states, the living will is superceded by the PoA.
- The ‘five wishes’ document is a form of living will that meets legal requirements in 42 states.
Provider Order for Life-Sustaining Treatment (POLST): (this is a medical order that MUST be followed)

- 43 states have some kind of POLST
  - 2 States (Oregon, West Virginia) have ‘mature’ programs
  - Illinois legislation passed (SB3076) and is among 28 states whose program is “developing
  - Similar to a living will, must be signed by a physician or licensed provider

- Whether the above supercedes a designated PoA varies from state to state
- Is binding to emergency medical personnel if kept somewhere readily accessible, such as on a refrigerator or front door
- Was initially designed for patients with terminal illness, but may be filled out by any patient

POLST gives patients three options:

1. Comfort measures avoiding transfer to hospital
2. Limited interventions of basic medical treatments and transfers to hospitals but avoiding ICU
3. Full treatment including transfer to hospital and ICU

- Resources: www.polstil.org
The Illinois Department of Aging provides complimentary copies of the following forms:

- Power of Attorney for Health Care
- Power of Attorney for Property
- Living Will

For copies, contact the Senior Helpline:

1-800-252-8966
1-888-206-1327 (TTY)

Email: ilsenior@aging.state.il.us
Thank you all for being here and for your commitment to improving the health and well-being of your clients

vgruss@uic.edu
Questions?
Website for the National Hospice and Palliative Care Organization, [http://www.nhpco.org/](http://www.nhpco.org/)

Website for the American Academy of Hospice and Palliative Care, [http://aahpm.org/](http://aahpm.org/)

GRS slides available at [http://GeriatricsCareOnline.org](http://GeriatricsCareOnline.org)


