Interprofessional Geriatrics Training Program

The Dying Process

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The Dying Process: Social and Personal Context

- Death is a universal experience, yet the dying process can be upsetting and unfamiliar
- Health care professionals are deeply ingrained in the person's dying process and clinicians should remember:
  - Each person's death is unique
  - Each person has their own understanding, views, and attitudes toward death
  - Personal attitudes toward death may change over the lifespan

Learning Objectives

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

1. Discuss death and dying in a social, cultural, and personal context
2. Describe the four domains of comfort care at the end of life
3. Identify non-pharmacologic and pharmacologic approaches to managing symptoms and issues of dying
4. List the signs of impending death
5. Recognize *The Conversation* instructions for end of life decisions
6. Summarize the value of the clinician's *Pause*, including how it can be applied to your practice

Culture and Diversity

The Dying Process: Culture and Diversity

- Cultural, spiritual, and religious beliefs [not in narration] and other contributing factors may affect the way patients and their families respond to death and the process of dying
  - Understand differences *between* and *within* different social groups

Culturally Relevant Issues

The Dying Process: Culture and Diversity

- Health providers and caregivers need to consider the following culturally relevant issues:
  - The patient and family's perspectives on:
    - Death and dying
    - Health and suffering
    - Hospice and palliative care services
    - Acceptance of Western health care practices
    - Use of alternative traditional practices

(S. Lopez, 2007)

The Dying Process: Culture and Diversity

- Health Providers and caregivers need to consider the following culturally-relevant issues (continued):
  - The roles of:
    - Spiritual and religious beliefs and practices
    - Family, including who is considered part of the family
    - The patient in problem-solving and the process of decision-making
  - How the patient and family communicates includes the need for an interpreter or culturally-relevant terminology around illness and dying

(S. Lopez, 2007)

Perspective

Death and Dying: Our Own Perspective

- Consider how our own personal experiences of death and the dying process may affect how we interact with patients and their end of life decisions
- Be aware of our own personal and professional beliefs about the dying process and end of life decisions
- Consult with others regarding the degree to which your attitudes, values, and beliefs could affect or bias the care you provide around death and dying

(American Psychological Association , 2015)

Stages of Death and Dying

- *On Death and Dying* by Elisabeth Kübler-Ross, MD, (1969) was a seminal work increasing our understanding of how people cope with and adjust to the reality of death and the dying process
- The book is based on numerous conversations with dying individuals
- Five Stages of Grief:
  - Denial
  - Anger
  - Bargaining
  - Depression
  - Acceptance

Comfort Care

Comfort Care: Approach to Death and Dying

- Comfort care is an essential part of medical care at the end of life
  - Helps or soothes a person who is dying
  - Goal: Prevent or relieve suffering as much as possible, while respecting the dying person's wishes

(National Institute on Aging, 2012)

Comfort Care Domains

- Comfort care near the end of life is comprehensive and addresses various domains:
  - Physical comfort
  - Mental and emotional needs
  - Spiritual issues
  - Practical tasks

(National Institute on Aging, 2012)

Assessment Question 1

Which of the following domains should be addressed when providing comprehensive comfort care to a dying patient?

a) Emotional

b) Physical

c) Practical

d) Spiritual

e) All of the above

Assessment Question 1: Answer

Which of the following domains should be addressed when providing comprehensive comfort care to a dying patient?

a) Emotional

b) Physical

c) Practical

d) Spiritual

e) All of the above (Correct Answer)

Physical Comfort Care

Physical Comfort Care: Pain

Non-Pharmacologic Approaches
Light massage (Hokka et al., 2014)
Cognitive-behavioral therapies (CBT): • Relaxation techniques (Hokka et al., 2014) • Guided imagery (Hokka et al., 2014) • Music therapy (Teut et al., 2014) • Prayer or meditation (Buck & Meghani, 2012)

Pharmacologic Approaches
NSAIDs (Campbell, 2015)
Antidepressants (Campbell, 2015)
Neuroleptics (Campbell, 2015)
Corticosteroids (Campbell, 2015)
Opioids: (Campbell, 2015) • Opioid naïve patients – Morphine 5 mg IV = 15 mg PO

Physical Comfort Care: Nausea

Non-Pharmacologic Approaches	Pharmacologic Approaches
Avoid foods with strong odors (Bischoff & Renzer, 2006)	Prochlorperazine 10 mg IV/PO q6h PRN (Ishiguro et al., 2013)
Avoid fried/fatty foods (Bischoff & Renzer, 2006)	Metoclopramide 10 mg IV/PO q6h PRN (Lindqvist et al., 2013)
Take most meds (except antiemetics) after eating (Bischoff & Renzer, 2006)	Haloperidol 1 mg IV/PO q6h PRN (Lindqvist et al., 2013)

Physical Comfort Care: Constipation

Non-Pharmacologic Approaches
Encourage fluid or fiber intake as appropriate
Activity as tolerated

Pharmacologic Approaches
Docusate Sodium 300 mg/daily (Campbell, 2015)
Senna 8.6 mg bid (Campbell, 2015)
Polyethylene Glycol 17 gm daily (Campbell, 2015)
Bisacodyl Suppository 10 mg PRN (Campbell, 2015)

Physical Comfort Care: Dyspnea (Difficulty Breathing)

Non-Pharmacologic Approaches
Comfortable positioning (Campbell, 2015)
Relaxation exercises: Prayer, meditation, or music (Pan et al., 2000)
Use a fan (Kamal et al., 2012)
Alleviate dry mouth (Labori et al., 2006)
Supplemental oxygen [not on narration] (Campbell, 2015)

Pharmacologic Approaches
For opioid naïve patients • Morphine 5 mg PO or 2 mg IV q1h PRN (Campbell, 2015; Sandvik et al., 2016)
For opioid tolerant patients • Use current PRN medication
Goal is respiratory rate (RR) < 22

Physical Comfort Care: Anorexia and Feeding Problems

- Symptoms that provoke the greatest distress in the last week of life include anorexia, fatigue, and cachexia
- Family members may be more concerned than the patient about anorexia
- Beliefs about feeding: improves quality of life, can help the illness, and increases lifespan

Reality

- Artificial hydration may increase suffering with pulmonary secretions, urinary output, nausea, vomiting, and edema
  - Oral intake naturally decreases as death nears; lack of water increases endogenous opiates
  - Decreased appetite is a normal part of the dying process, allay fears of "starving to death"

(Ishiki et al., 2015)

Physical Comfort Care: Feeding Problems

Feeding Problems	Approaches
Early satiety (Ribera-Casado, 2014)	Offer small, frequent meals, use salad plate/saucer, keep favorite foods on hand, offer sips and nibbles
Difficulty swallowing (Buning & Bullock, 2015)	Provide mouth care, swabs
Patient hungry [addressed in upcoming narration]	Provide thickened liquids, yogurt, and ice cream
Nausea or vomiting (Bischoff & Renzer, 2006)	Eliminate offending foods, tastes, and smells Provide cold or room temperature foods, bland foods, and avoid eating or drinking 1-2 hours after vomiting

High Quality Alternative to Tube Feeding: Intensive Individualized Comfort Care

- Perception by family that health care staff lack concern and their family member is "starving to death" often leads to inappropriate use of feeding tubes
- The frequently used phrase "comfort measures only" implies that care is being limited or diminished
- Likewise, the more recent term "comfort feeding only" suggests that the quality of meals and assistance provided will be limited or lessened in some fashion

(Palecek et al., 2012)

High Quality Alternative to Tube Feeding: Intensive Individualized Comfort Care

- Instead, Dr. Ruth Palan-Lopez (2012) proposes that family members be provided with the option of "intensive individualized comfort care"
- Aims of this paradigm of care are to aggressively seek and attain comfort to meet individual patient needs and provide family member support

(Palecek et al., 2012)

High Quality Alternative to Tube Feeding: Intensive Individualized Comfort Care

- Applying the principles of intensive individualized comfort care to this larger view of mealtimes, Dr. Palan-Lopez (2012) suggests that three components of mealtime should be addressed within the context of meals as a shared experience: past, present, and future
- Those implementing intensive individualized comfort care for mealtimes should encourage family members to provide information about food preferences, values and beliefs, and cultural background to create individualized meal plans
- They should use familiar foods, flavors, and rituals as a means of remaining connected to the individual and maintaining their familial relationships, while little emphasis should be placed on weighing or counting calories

(Palecek et al., 2012)

Physical Comfort Care: Other Physical Symptoms

- Fever and headache
  - Acetaminophen 650 mg PO/PR q4h PRN
- Upper airway secretions
  - Scopolamine patch q72h (Lindqvist et al., 2013)
  - Glycopyrrolate 0.2-0.4 mg IV q6h PRN (Lindqvist et al., 2013)
- Dry eyes
  - Ocular lubricant ointments, as directed
- Insomnia
  - Zolpidem 5 mg nightly PRN (MacFarlane et al., 2014)
  - Lorazepam 0.5 mg IV/PO nightly PRN (Lindqvist et al., 2013)
  - Behavioral approaches: relaxation, environmental changes, etc. [not in narration]

Mental and Emotional Needs

Comfort Care: Mental and Emotional Needs

- Each person and his/her family will have a unique response to illness and impending death
  - Nature of the illness
  - Past experience with death
  - Stage of the life cycle
  - Coping skills/past coping
  - Cultural values
  - Family structure and support
  - Spirituality/religious resources
  - Other stressors [not in narration]

(Endacott et al., 2016)

Comfort Care: Mental and Emotional Needs

Behavioral Approaches
Validate feelings (Chochinov et al., 2005)
Increase opportunities for control
Treat underlying symptoms (Dy et al., 2008)
Chaplain~~cy~~, social worker, or psychiatric consult (Haley et al., 2003)

Pharmacologic Approaches
Lorazepam 0.5 mg IV/PO q6h PRN (Lindqvist et al., 2013)
Clonazepam 0.5 mg q8h PRN (Lindqvist et al., 2013)

Comfort Care: Mental and Emotional Needs

- Common issues patients confront during the dying process:
  - Coming to an understanding of the meaning of the illness (Breithart et al., 2004)
  - Loss of dignity or function (Chochinov et al., 2005)
  - Dependency or becoming a burden to others (Chochinov et al., 2005)
  - Fear and anxiety (Chochinov et al., 2005)
  - Loss of control of self (Chochinov et al., 2005)
  - Death itself (Chochinov et al., 2005)

Comfort Care: Mental and Emotional Needs Agitation

Non-Pharmacologic Approaches
Keep room dark during the night (Barr et al., 2013)
Reduce external stimuli (Barr et al., 2013)
Reorient as needed (Irwin et al., 2013; Martinez et al., 2012)
Talk softly and calmly; explore and address unmet needs (Ersnang Alnes et al., 2011)
Keep familiar objects in the room (Martinez et al., 2012)
Avoid physical restraints (Skrobik, 2011)

Pharmacologic Approaches (not all with an approved indication)
Haloperidol 1-2 mg IV/PO q6h (Campbell, 2015; Sandvik et al., 2016)
Olanzapine 2.5 mg-5 mg nightly (Campbell, 2015)
Chlorpromazine 25-50 mg q6h (Lindqvist et al., 2013)
Lorazepam 0.5-1 mg q6h (use with caution) (Campbell, 2015; Sandvik et al., 2016)

Spiritual Issues

Comfort Care: Spiritual Needs
Anticipatory Grief and Family Issues

Anticipatory Grief

"Encompassing the process of mourning, coping, interaction planning, and psychosocial reorganization that are stimulated and begin in part in response to the awareness of the impending loss of a loved one and recognition of associated losses in the past, present, and future"

(Rando, 1986, p. 24)

Comfort Care: Spiritual Needs
Anticipatory Grief and Family Issues

Anticipatory grief allows families to prepare for the death of their loved one

- Allows the idea of the loss of the person to "sink in"
- Families may address unresolved interpersonal issues as necessary
- Provides time for planning for funerals
- Allows the process of adjustment and healing to begin

(Rando, 1986)

Comfort Care: Spiritual Needs
Grief and Healing After the Loss of a Loved One

- Bereavement affects people in numerous ways, including behaviorally, cognitively, interpersonally, emotionally, physically, and spiritually (Shear et al., 2013)
- Key elements of the mourning process:
  - Accepting the reality of the loss
  - Processing the pain of grief
  - Adjusting to an environment without the deceased
  - Withdrawing emotional energy from the deceased and investing it in other relationships (Worden, 2009)

Comfort Care: Spiritual Needs
Grief, Mourning, and Bereavement

- Grief: Emotional reaction to loss
- Mourning: Process of adjusting to the void created by the loss
- Bereavement: The period after a loss when grief is experienced and mourning takes place
- Losses occur during the entire dying process, not only at the moment of death

(Hagman, 2016)

Assessment Question 2

Clara is a 68-year-old woman in hospice who repeatedly expresses anxiety about dying out of fear of God's punishment for her past misdeeds. To help Clara, you might consider:

a) Telling Clara that her fears are unfounded
b) Asking Clara if she would like to speak with a Chaplain
c) Sharing your own fears of death with Clara
d) Suggesting to Clara that she pray for forgiveness
e) None of the above is an appropriate response

Assessment Question 2: Answer

Clara is a 68-year-old woman in hospice who repeatedly expresses anxiety about dying out of fear of God's punishment for her past misdeeds. To help Clara, you might consider:

a) Telling Clara that her fears are unfounded

b) Asking Clara if she would like to speak with a Chaplain (Correct Answer)

c) Sharing your own fears of death with Clara

d) Suggesting to Clara that she pray for forgiveness

e) None of the above is an appropriate response

Practical Tasks

Comfort Care: Practical Tasks
End of Life Decisions – *The Conversation Project*

What Do People Want at the 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 so (Conversation Project Survey, 2013)
- 82% of respondents said it was important to put their wishes in writing, but only 23% have actually done it (California Healthcare Foundation, 2012)

Practical Tasks: End of Life Decisions – *The Conversation Project*

- *The Conversation Project* from the Institute for Healthcare Improvement (IHI)
  - Goal of *The Conversation Project*: To ensure that everyone's end of life wishes are expressed and respected
  - Includes step-by-step instructions for how to consider and discuss crucial end of life issues
    http://theconversationproject.org/

(Conversation Project National Survey, 2013)

Assessment Question 3

The goal of The Conversation Project from the Institute for Healthcare Improvement (IHI) is to:

a) Ensure everyone's end of life wishes are expressed and respected
b) Have a conversation about the family's values and wishes
c) Allow the provider to voice his/her opinion about clinicians' end of life values
d) Discuss the costs of end of life care

Assessment Question 3: Answer

The goal of The Conversation Project from the Institute for Healthcare Improvement (IHI) is to:

a) Ensure everyone's end of life wishes are expressed and respected (Correct Answer)
b) Have a conversation about the family's values and wishes
c) Allow the provider to voice his/her opinion about clinicians' end of life values
d) Discuss the costs of end of life care

Practical Tasks

Practical Tasks: Communication

Effective Communication is Essential to End of Life Care

- Listening is key to understanding the patient's wishes, concerns, fears, etc. (Sinuff et al., 2015)
- Honesty is important (Sinuff et al., 2015)
- Be willing to talk about death (Sinuff et al., 2015)
- Be sensitive in delivering bad news to the patient and the family (Rollins & Hauck, 2015)

Practical Tasks: End of Life Decisions

Advanced Directives

- Living Will: Allows a person to put into writing wishes about medical treatments for the end of life in the event that they cannot communicate these desires directly
- Health Care Power of Attorney: Also called a "health care proxy," a person designated by the patient to make health care-related decisions in the event that the patient is incapacitated

Practical Tasks: End of Life Decisions

Advanced Directives

- Valid in all 50 states and become effective immediately
- No attorneys are needed for advanced directives, but some states have their own particular wording

  www.caringinfo.org

Advanced Directives: POLST

Advanced Care Planning Using a Medical Order

- Provider Order for Life-Sustaining Treatment (POLST)
- POLST is a medical order that MUST be followed
- Opportunity to discuss other options:
  - IV solutions
  - Feeding tubes
  - Pain medications
  - Hospice treatment
- In addition to MDs, [not in narration] it gives PAs, APNAs, and senior medical residents the power to sign the medical directive

Advanced Directives: POLST

Advanced Care Planning Using a Medical Order (Continued)

- www.polstil.org
- Find your state program: http://www.polst.org/programs-in-your-state/

Assessment Question 4

A living will is an important document in end of life care because it:

a) Provides information about the patient's wishes regarding medical treatment

b) Tells the patient's survivors how to dispense the patient's assets upon death

c) Can serve as a reference if the patient is uncommunicative

d) All of the above

e) Options a and c only

Assessment Question 4: Answer

A living will is an important document in end of life care because it:

a) Provides information about the patient's wishes regarding medical treatment

b) Tells the patient's survivors how to dispense the patient's assets upon death

c) Can serve as a reference if the patient is uncommunicative

d) All of the above

e) Options a and c only (Correct Answer)

Practical Tasks

Practical Tasks: End of Life Decisions – *Five Wishes*

***Five Wishes* Document**

- Recognized as meeting legal requirements for advanced directives in 42 states
- In the other 8 states it can be attached to the state's form
- Uses everyday language to guide the user through the process of specifying end of life wishes — personal, spiritual, medical, and legal
- Useful tool for family discussions
- Copyrighted

(Aging with Dignity, 2015)

Practical Tasks: End of Life Decisions – *Five Wishes*

Five Wishes

- Wish 1: *The person I wish to make decisions for me when I can't make them for myself*
  - Health care power of attorney who can interpret the instructions based on his/her understanding of the patient's wishes
- Wish 2: *My wish for the type of medical treatment I want or don't want*
  - Allows the person to define what "life support treatment" means to him/her
  - Expresses general instructions for health care providers and caregivers
  - Can be tailored to specific health statuses, such as coma or has severe brain damage
  - Allows for personalization
  - It is NOT a Do Not Resuscitate (DNR) order or a POLST order
  - It is considered a living will and is useful for discussing a DNR order

(Aging with Dignity, 2015)

Practical Tasks: End of Life Decisions – *Five Wishes*

Five Wishes

- Wish 3: *My wish for how comfortable I want to be*
  - Stresses that you want your pain managed properly
  - Allows you to indicate how alert and/or medicated you wish to be
  - Provides direction regarding comfort care
- Wish 4: *How you want people to treat you*
  - What others should keep in mind if you become seriously ill
  - Whether you want people around you and/or physically touching you
  - If you want prayers said for you
  - Ideas for your surroundings (e.g., photos of loved ones)

(Aging with Dignity, 2015)

Practical Tasks: End of Life Decisions – *Five Wishes*

Five Wishes

- Wish 5: *What you want your loved ones to know*
  - Allows you to express deep sentiments about your relationships with family and friends
  - Allows you to offer love and forgiveness to those who have hurt you
  - Communicates practical matters concerning burial wishes

(Aging with Dignity, 2015)

Practical Tasks: Additional Considerations

- Vital signs: May no longer be necessary
- Foley catheter: For comfort and to avoid having to toilet
- IV Fluids: May be discontinued as they can promote suffering at end of life
- De-prescribing medications [not in narration]

(Aging with Dignity, 2015)

Practical Tasks: Signs of Impending Death

Assess	Signs of Impending Death
Activity	Extreme weakness, mouth droop, minimal voluntary movement
Nutrition	Anorexia
Elimination	Oliguria, bowel incontinence/diarrhea
Pain	May be increased or decreased
Skin	Cyanosis, mottling, cooling

Practical Tasks: Signs of Impending Death

Assess	Signs of Impending Death
Sleep	Decreased responsiveness, frequently unarousable
Eyes	Glazed fixed stare, partly open, dilated pupils
Respirations	Death rattle, tachypnea, Cheyne-Stokes pattern
Neurological	Delirium, decreased arousal, may see a "rally"
Ascites/Edema	Decreased distention, decreased edema

Assessment Question 5

Signs of impending death include all the following except:

a) Extreme weakness, mouth droop, minimal involuntary movement

b) Improved appetite

c) Cyanosis, mottling, cooling

d) Death rattle, tachypnea, Cheyne-Stokes pattern breathing

Assessment Question 5: Answer

Signs of impending death include all the following except:

a) Extreme weakness, mouth droop, minimal involuntary movement

b) Improved appetite (Correct Answer)

c) Cyanosis, mottling, cooling

d) Death rattle, tachypnea, Cheyne-Stokes pattern breathing

The Clinician's *Pause*

- Witnessing death over and over again takes a toll
  - Over time, clinicians can become numb or burned out
  - One solution is the *Pause*, developed at the University of Virginia, Charlottesville, in which following the death of a patient everyone stops, and pauses
- The *Pause*
  - The team just stops and pauses, just for a minute
  - "It makes it so we can actually view the person as a person rather than as a patient that we see on an everyday basis," Jack Berner, EMT

(Lofton, 2015)

The Clinician's *Pause*

- The *Pause* (continued)
  - "You can relate more to the case [knowing] it's somebody's father or mother, their sister or uncle, rather than somebody you just see for five minutes" (Jack Berner)
  - The idea began to spread throughout their hospital, particularly to emergency department workers
  - The *Pause*, as it has become known, also is being taught as part of the curriculum at UVA in Charlottesville
  - Jack Berner says it helps him handle the toughest cases

(Lofton, 2015)

The Clinician's *Pause*

- The *Pause* (continued)
  - They hope the *Pause* will help medical workers like Berner accept the loss without disconnecting emotionally
  - "So you are able to feel and you are also able to sense and give back," Berner said, even if it's not a relative, a worker can have a sense of being a part of a loss
  - "I can also acknowledge the pain that I bore witness to in caring for that family and caring for that patient" (Jack Berner)

(Lofton, 2015)

Summary

- Death and dying is affected by social, cultural, and personal contexts
- There are four domains of comfort care at the end of life that require both non-pharmacologic and pharmacologic approaches to managing symptoms and issues of dying

  These domains are:
  - Physical
  - Mental and emotional issues
  - Spiritual issues
  - Practical tasks

Summary

- There are numerous signs that indicate impending death
- *Five Wishes* and *The Conversation* are two useful tools patients can use to provide instruction for their own end of life care
- The clinician's *Pause* allows the clinical team to stop for a moment out of respect for the person who has died and to center themselves in the midst of performing the numerous tasks of caring for the dying and deceased

Resources

https://agingwithdignity.org/five-wishes/about-five-wishes Accessed October 10, 2016

www.caringinfo.org Accessed October 10, 2016

http://theconversationproject.org/ Accessed October 10, 2016

http://www.polst.org/programs-in-your-state/ Accessed October 10, 2016

https://hospicefoundation.org/End-of-Life-Support-and-Resources/Coping-with-Terminal-Illness/Signs-of-Approaching-Death Accessed October 10, 2016

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