Bryan Heart Nurses Conference
October 2018

Objectives

- At the end of this presentation, participants will:
  - Understand the difference between Palliative Care and hospice care
  - Have a greater understanding of advance care planning and end of life decision making
  - Have increased confidence when talking with patients about end of life issues

Definitions

- Hospice Care
  - Impending death
  - 6 months
  - Delivered anywhere
  - Interdisciplinary team
  - Covered by Medicare, Medicaid, and insurance

Definitions

- Palliative Care
  - Optimizes QOL
  - Life-limiting illness
  - Specialized medical care provided by interdisciplinary team
  - Extra layer of support
  - Appropriate at any age and any stage
  - Can be provided along with curative treatment
  - Approx. 2 year prognosis
  - Covered by Medicare, Medicaid, and insurance

Evolution of Palliative Care

- Hospice nursing England to US 1970's
- Medicare benefit 1982
- Over the last 30 years realized more patients could benefit from time of diagnosis to time of death
- This care differentiates the care rendered under hospice

Palliative Care is a Medical Specialty

- Clinical practice guidelines
- Structured system for delivery of care
- PC supports the patient and family by supporting their hopes and goals for cure, for prolonging hope, as well as peace and dignity throughout the illness and their death.
- Requires specific training and certification in both the RN and advance practice role

Palliative Care patients

- Cancer
- Pulmonary disorders
- Renal and Hepatic disorders
- Heart Failure
- Progressive Neuro conditions
- HIV/AIDS
- Acute conditions with multiple co-morbidities
- ANY SERIOUS, CHRONIC CONDITION

PC CONSULTS

8 DOMAINS OF PC

1. Structure and processes of care
2. Physical aspects of care
3. Psychological aspects of care
4. Social aspects of care

Domains

5. Spiritual and religious aspects of care
6. Cultural aspects of care
7. Care of imminently dying patients
8. **Ethical and legal aspects of care**

Autonomy

40 year old female with recurrent breast cancer. Curative treatments for years. Now wants to enjoy her family with time she has left. Understands her time is limited. Discussed with her family, pastor, physicians. We do NOT have the right to try to change her mind if she is informed and decisional despite the medical teams feeling perplexed.

A 66 year old male with CHF. All options for medically managing his heart failure have been exhausted. He wants to be a FULL CODE. He wants aggressive treatment despite being told it will not help him.

The key here is ***CAPACITY.***

Beneficence

- 56 year old ALS patient now on noninvasive ventilation. PEG tube in place previously. His wish is to die at home.
- We honored his wishes to die at home. Within one hour after transfer, he passed away at home with his family.

Non-Maleficence

- Patient with CHF made the decision for no more treatment and wants comfort cares. Became progressively somnolent but nurses note he grimaces when turning him. Nurses are fearful of giving him morphine which could cause more sedation. They asked for guidance. If given in appropriate doses this will NOT hasten the death of the patient but will lessen his suffering.

Justice

- Early in the 2000s focus was on the aging population, but now push is to also focus on vulnerable populations – substance abuse, homelessness, uninsured.
- The role of RNs and APRNs continues to evolve in PC.

Decision Making

- Who makes the health care decisions?
  - Medical term not a legal term
  - Patient or Surrogate
  - HCPOA only invoked if patient not decisional.
  - Focus is on: does the patient understand their health status or disease and the consequences of treatment options.

Advance Care Planning

- Only 15-25% of Americans have an advance directive
- 63% of Nebraskans have heard of PC
- 29% of Nebraskans have completed an advance directive
- 43% of Nebraskans are comfortable talking about their own death

Advance Directive

- Should name a surrogate (HCPOA)
- Surrogate is used only when patient is unable to participate in decision making
- All family members should know
- If no HCPOA – spouse, children (State laws vary)

Advance Directive helpful with:

- Code status decisions
- Medical Futility
- Benefit vs. burden of therapy

EOL Decisions

- Use term “allow a natural death” rather than DNR
- Patients have the right to accept or refuse treatments
- Consideration of “trial of treatment”
- Many struggle with nutrition questions

Talking Points

- Barriers to Communication:
  - Previous experience with loss or hospice care
  - Anticipatory grief
  - Cultural differences
  - Physical impairments
  - Psychological issues

Before going in….

Reason for Consult

Advance Directive

Diagnosis

Trajectory of disease/prognosis

Code status

Discussion of ACP/Goal setting

- ***Early goal setting:***
  - Should be done as outpatient
  - Do you have advance directive?
  - They are adjusting; don't hurry
  - Ask their opinion
  - Talk about their values
  - Don't lead with code discussion
  - Don't force a decision

Early goals (continued)

- Suggest a surrogate
- Expect emotion
- What do I need to know to take better care of you?
- If goals are unrealistic – don't try to talk them out of them on first meeting; endorse the realistic ones
- Assess readiness
- Create some distance to make the talk safer
- Praise for being successful; thank them

Late goals

- Redirect the patient
- Expect emotion
- Don't move on to what's not working or code status; talk about values again
- Show that you heard
- Lead into what you need to talk about
- Talk about treatments that align with their values
- "Do everything"

Late goals (continued)

- Can't they do anything for me?
- Trial treatment
- Don't say "Yes, but….."
- Instead say "Yes, and……"
- If patient too sick to talk……"If Joe would talk to us what would he say?" Shift the focus to patient.
- Talk about CPR/code status LAST.
- Don't say "He's dying." Acknowledge medically first.

Emotions

- Put the emotions you are seeing into words
- Then "understand"
- Respect them for what they are doing well
- Support them
- If stuck and not sure where to go from here….ask for more.

Emotions (continued)

- PAUSE
- "Name it to tame it"
- Before you go on……acknowledge the emotion first, then give more information
- Don't overwhelm
- Before you leave the room ….

Imparting Serious or Bad News

- "I'm a little nervous"
- Quiet place (IMPOSSIBLE)
- Sit down
- What have you heard?
- Inform with a one sentence headline:
  "THE BIOPSY SHOWED CANCER"
- Expect and respond to emotion
- You can't predict emotion but you can tailor your response

Serious News (continued)

- Explain what happens next
- If confused…..ask "what is going through your mind right now?

Dying

- Are you at peace?
- Are you worried about anything?
- "I think your reaction is normal. Tell me more about what you're thinking." This enables coping
- Let the patient lead….
- Say goodbye so patient does not feel abandoned
- Say goodbye early
- It's about appreciation
- Awkward moments

Conflicts

- Inescapable
- Don't debate
- Don't interrupt
- Learn the "other side"
- Tap into SLOW THINKING
- Do a "soft start"
- Use neutral language
- EMPATHY
- Create new options if possible
- If no progress find a third party

Family looks mad…..

- Show you are willing to listen
- Give them the opening

Anger

- "With all respect, that tone of voice makes it hard for me to listen."
- "I think we should take a break. I will be back in _____"

When the patient is mad at you…

Don't make excuses

Apologize

"I heard you have some concerns. I want to try to help."

SUMMARY

- Don't try to solve the family's issues.
- Stay neutral.
- Keep the focus on the patient's values.
- Avoid lecturing or giving your opinions or feelings
- Align with the patient or family
- Don't recommend if you're not asked to.
- They have their own personal views.

EMPATHIZE-EMPATHIZE-EMPATHIZE