Addressing End-of-Life Issues

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Following the program, participants should be able to:

- Define advance care planning and explain its importance
- Describe the steps of advance care planning and how they interrelate
- Understand the principles behind breaking bad news and negotiating goals of care
- Familiarization with ELNEC, the National Consensus Project and National Quality Forum
- Symptom Management
Questions...

• How many know of the End of Life Nursing Education Consortium and have taken ELNEC?
• How many have taken any classes that addressed caring for the dying patient?
• How many know of the National Consensus Project?
What are the Goals of Care or GOC?

Medicine has historically has strived towards two primary goals:

1. Curing Illness
2. Relieving Suffering

The emerging dilemmas:

• Should the relief of suffering be compromised by the quest for cure?
• When is it time to stop the quest?
What are Advanced Directives?

Healthcare Proxy (HCP): Documents that give the power to make decisions on healthcare to specific persons when the patient looses capacity. They can over-ride Living Wills. HCPs are not the same as power of attorney.

Living Wills: Documents which outline what the patients wishes are regarding healthcare and quality of life. They can be trumped by the HCP and can be misconstrued because they often cover every circumstance and are loosely worded.
Why?

• Provides a framework for advanced medical care
• Delineates preferences, goals and values
• Formalizes parameters that define basic quality of life
• Professional and legal responsibility
• When clinicians take part it promotes a trusting relationship
• Promotes peace of mind by planning for the worst so one can hope for the best
Who should have them?

- EVERYONE who can make decisions about their healthcare & quality of life
- ANY age
- Healthy and Ailing
When?

- Plan in advance & schedule
- When “healthy”
- Before doing will so it can be incorporated
- Should be adapted periodically
- Before planned hospitalizations
- Easily distributed amongst proxies and significant others
- Before the elephant is in the room
How?

• Forms and directions are available online
  – Google: Healthcare Proxy and Living Will
• Forms are available at most healthcare institutions
• Make sure it is done in a “safe” and comfortable setting
• 5 Steps for successful advance care planning
  (Emanuel 2007)
Step 1: Introduce the topic

- Be straightforward and routine
- Determine patient familiarity
- Explain the process
- Determine comfort level
- Determine proxy
Step 2: Engage in structured discussions

- Proxy decision maker(s) present
- Describe Scenarios, options for care
- Elicit patient’s values and goals
- Write it all down
- Check for inconsistencies
Step 3: Document Patient Preferences

Step 4: Review and Update

Step 5: Apply Directives When Need Arises
Being Present is in itself therapeutic

“The very most we can do for patients is to make it better ... by our presence and concern ... than it would have been if we were not there.” (Rando 1984)

However, doing something about the problem can have great impact...
Planning Pitfalls

• Poor Proxies
  – Emotional pressure on HCP
  – Patient coerced into HCP choice
  – Can be forged

• Living wills are not legal documents
  – Serve as a guide for decision making
  – Unable to anticipate all scenarios
  – Can be over ridden by HCP
POLST = MOLST

Physician Orders for Life-Sustaining Treatment

Medical Orders for Life-Sustaining Treatment
POLST PARADIGM

http://www.polst.org/programs-in-your-state/
Addressing the Elephant in the Room
When to initiate end-of-life discussions

- When the patient is facing imminent death
- Patients talk about wanting to die
- Inquiries about hospice
- Recent hospitalization for severe progressive illness
- Suffering is disproportionate to prognosis
- When discussing prognosis
- When discussing treatments with low probability of success
- When discussing hopes and fears

Quill, JAMA, 2000
6 Step to Delivering Bad News

1. Arrange to meet in a private setting where you will not be interrupted

2. Establish what the patient/family already know

3. Identify how much they want to know

4. Share the diagnosis and Prognosis with them then present various treatment options available while presenting a realistic appraisal of the benefits vs. burdens

5. Respond to their feelings and identify and acknowledge their reactions

6. Formulate a plan of care and establish a contract for the future

EPEC Project, 1999
Truth – Telling & Maintaining Hope

The inherent conflict between the desire to know the truth with its consequences and the benefit of maintaining optimism can undermine good communication & GOC.

“Hoping for the best while planning for the worst” is an approach which can strike the needed balance between discussing the truth without taking away hope.
Multiple Goals of Care

Simultaneous Goals: the patient and care team seek both control of disease and symptom management and interventions that sacrifice either are not considered.

Contradictory Goals: the patient wants prolongation of life at all costs without forfeiting comfort.

Prioritized Goals: relative weight given to goals change dependent on the perception the patient has during a particular period of life or during the illness which may lead to conflict.

EPEC Project, 1999
Skills for dealing with challenging situations

- Anger and conflict resolution
  - What triggers your anger? Which patients/families make you angry? What are my underlying feelings when I am angry: humiliation, rejection, shame, powerless, depressed.

- Challenging (“difficult”) patients and families
  - Entitled demanders, borderline, dependent clingers; manipulative help rejectors

- Dying patients
  - If I were dying, what would I need from my physician? How does a patient’s death make me feel about myself as a clinician? How have I dealt with losses / setbacks / bad news before? Did that work for me? How do my role models deal with dying patients?

Novack et al 1997
7-Step Protocol to Negotiate GOC

1. Create the right setting
   find a quiet moment, sit down

2. Determine what the patient/family know
   ask what they have been told and what that means to them

3. Explore what they are hoping for
   ask what they think the future holds

4. Suggest realistic goals
   talk about the natural course patients in similar circumstances and what can be expected

5. Respond empathetically

6. Make a plan and follow through

7. Review & revise prn

EPEC Project, 1999
Although the world is full of suffering, it is also full of the overcoming of it.

Helen Keller

*Optimism, 1903*
Quality Care at the End of Life

- End of Life Nursing Education Consortium ~ ELNEC
- National Consensus Project ~ NCP
- National Quality Forum ~ NQF
- Oncology Nursing Society ~ ONS
ELNEC – caring for the imminently dying

- **Psychologic and spiritual symptoms**: fear of the dying process, abandonment and unknown; nearing death awareness followed by withdrawal from family and friends, increased focus on spiritual issues

- **Physical signs and symptoms**: delirium, weakness, fatigue, drowsiness and decreased responsiveness, decreased oral intake, decreased or lack of swallow reflex, surges of energy, restlessness/terminal agitation, fever, bowel changes, incontinence

- **Universal symptoms of imminent death**: decreasing urine output, cold and mottled extremities, vital sign changes, respiratory congestion (death rattle), breathing pattern changes, delirium, restlessness, coma
NCP

• 2001: National Consensus Project for Quality Palliative Care evolved from a combined effort on the part of:
  – Hospice and Palliative care Nursing Association (HPNA)
  – American Academy of Palliative Medicine (AAHPM)
  – National Hospice and Palliative Care Organization (NHPCO)
  – Center for the Advancement of Palliative Care (CAPC)
  – Partnership in Caring: America’s Voice for the Dying

• 2004: Clinical Guidelines for Palliative Care & its 8 domains for quality palliative care
The National Consensus Project for Quality Palliative Care (2004)

- Promote implementation of clinical practice guidelines
- Ensure care of consistent and high quality
- Guide the development and structure of new and existing palliative care services
- HPNA, AAHPM, NHPCO, CAPC, & Partnership in Caring: America’s Voice for the Dying
- 8 Domains of Quality Palliative Care
  http://www.nationalconsensusproject.org
NCP Domains of Quality Palliative Care

- The guidelines describe core precepts and structures of clinical palliative care programs divided into eight dedicated sections:
  - Structure and Processes of Care
  - Physical Aspects of Care
  - Psychological and Psychiatric Aspects of Care
  - Social Aspects of Care
  - Spiritual, Religious and Existential Aspects of Care
  - Cultural Aspects of Care
  - Care of the Imminently Dying Patient
  - Ethical and Legal Aspects of Care
National Quality Forum (NQF)

  - Based largely on the NCP’s Guidelines
  - First step in the development of a quality measurement and reporting system for palliative care and hospice services
NCP & NQF: Similar But Different

**NCP Guidelines**
- include extensive background on the history and philosophy of palliative care and are carefully referenced to the evidence base from which they are drawn
- intended to provide guidance across a range of palliative care delivery settings
- present recommended practices within each domain

**NQF Framework**
- the first step in a process through which rigorous, quantifiable internal and external quality indicators are developed
- provides a concise structural definition of quality palliative care
- provides a set of 38 “preferred practices”
- will lead to palliative care standards with implications for reimbursement, internal and external quality measurement, regulation, and accreditation

The NCP recommends that the two documents be used in conjunction to guide the development of new palliative care programs, improve existing ones, and demonstrate compliance with consensus standards for quality palliative care.
NQF

• 2006: utilized NCP’s 8 domains to build the National Framework and Preferred Practices for Palliative and Hospice Care Quality Report

• Defines preferred practice and facilitates use of NCP Guidelines.

• NQF identified 38 best practices

• #26 – 31 refer to care of imminently dying aka... domain 7
8 Domains...

- Structure and process of care
- Physical aspects of care
- Psychosocial and psychiatric aspects of care
- Social aspects of care
- Spiritual, religious, and existential aspects of care
- Cultural aspects of care
- Care of the imminently dying patient**
- Ethical and legal aspects of care
NQF preferred practices related to care of the imminently dying

• 26: Recognize and document the transition to the active dying phase and communicate to the patient, family and staff the expectation of imminent death
  - Ask-tell-ask
    • Ask the patient & family about their sense of how the patient has been doing and what this means in terms of their disease process
    • Tell them what you see in terms of change in function, symptoms, and physiologic parameters and what it means.
    • Ask about the impact of the information and what would be helpful now.
    • End by making a plan for the next steps, including on going care, communicating with other family members and significant others & education about dying

Lynch & Dahlin 2007
NQF preferred practices related to care of the imminently dying (cont’d)

• 27: Educate family in a timely manner regarding the signs and symptoms of imminent death in an age appropriate, developmentally appropriate and culturally appropriate manner.
  – Take cues from children as to what they want to know about dying and what the dying patient means to them
  – Use simple terminology & expect to repeat information

• 28: As a part of the ongoing care planning process, routinely ascertain and document patient and family wishes about the care setting for site of death and fulfill patient and family preferences when possible
  – Is home possible? What supports are available? Care requirements? Financial implications? Is there favorite music and memorabilia available?

Lynch & Dahlin 2007
NQF preferred practices related to care of the imminently dying (cont’d)

• 29: Proved adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns and fears about use of narcotics and of analgesics hastening death
  – Properly treating symptoms with opioids does not hasten death.
  – Document symptoms and effect of treatments

• 30: Treat the body after death with respect according to the cultural and religious practices of the family and in accordance with local law.
  – Post mortem care should delivered with the same compassion as caring for the living
  – Knowledge of institutional policies regarding disposition of the body is key in comforting families.

Lynch & Dahlin 2007
NQF preferred practices related to care of the imminently dying (cont’d)

• 31: Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient’s death when the family remains the focus of care.
  – Although there is no evidence associating routine grief interventions with easing bereavement, those who seek support generally benefit & having easily accessible resources can help.
  – Explain that everyone processes loss differently - it takes months and sometimes years to come to terms – it is a normal process.

lynch & Dahlin 2007
Oncology Nursing Society and Association of Oncology Social Work Joint Position on Palliative and End-of-Life Care

http://www2.ons.org/Publications/Positions/EndOfLife

It says the same things in a different way...
Three Pillars of the ONS and AOSW Position Statement

✓ Patient and Family Care:
  ✓ Palliative care begins when appropriate and continues through bereavement.
  ✓ Family centered – unit of care.
  ✓ Effective communication between patient, family and care team is facilitated and prioritized by interdisciplinary (interprofessional) team in a manner that enhances and empowers.

✓ Integrated Care Systems:
  ✓ Healthcare systems adopt POLST (in MA its MOLST).
  ✓ 24-7 palliative care availability across the continuum at every point of contact in the healthcare system.
  ✓ Communication regarding patients includes values, goals, needs as well as clinical and psychosocial issues.

✓ Public Advocacy:
  ✓ Public and professional education regarding the preparation of advanced healthcare directives and the right of each individual.
  ✓ Skilled advocacy in collaboration with regional and national policymakers, consumer groups, licensing, regulatory agencies focusing on affordable access to EOL care and the establishment of prescribing laws that enable the adequate relief of pain.
Symptom management: PAIN

Morphine is the gold standard – except in renal failure.
Start low and treat aggressively with boluses, do not dial up the drip to comfort.
Long acting including drips only when pain is controlled and it is known what the patients require to control pain
Constantly reassess and document pain, treatment and response.
PRN dosing calculation is 10-20% of total 24 hr requirements
Symptom management: Dyspnea

- Common
- Morphine and all other opioids effect the breathing center in the brainstem
- Dosing is similar to pain only at about 50% of the requirement
- May need to alternate with a benzo (generally lorazepam) so that the anxiety component of air hunger is relaxed
Symptom management: Delirium

- Treat underlying cause if you have time
- HALDOL is the gold standard however everyone is afraid of it because of its QT prolongation issues, extraparamital side effects and lowering seizure thresh hold
- IF it is terminal delirium it can be beneficial to use a benzo to sedate the person as there is little chance the delirium will reverse with an antipsychotic or the requirements may be so high that you may have dose related complications – the things people fear.
Symptom management: secretions

- Determine composition of secretions: salivary, mucous or mixed
- If strictly salivary – use an anticholinergic such as glycopyrrolate or scopolamine
- If mucous – NO ANTICHOLINERGIC as they can cause plugs and worsen dyscomfort – use NS Nebs and suction
- If mixed – same as mucous
On line resources:

- EPERC fast facts: http://www.eperc.mcw.edu/EPERC/FastFactsandConcepts
- ONS end-of-life: http://www2.ons.org/Publications/Positions/EndOfLife
- ELNEC: http://www.aacn.nche.edu/elnec
- City of Hope & Betty Ferrell: http://www.cityofhope.org/people/ferrell-betty
discussion?