Advanced Care Planning and Advanced Directives: Our Roles

March 27, 2017

2017 NPSS
Asheville, NC
Overview

- History of Advanced Directives
- Importance of Advanced Care Planning for Quality care
- Our Role in Advanced Care planning
- DNR
- MOST
- Documentation
Medical Progress

...has changed the way we live

...has changed the way we are sick

...has changed the way we die
Changes in the way we die

• 20th century-
  – Antibiotics
  – Feeding tubes – bridge to recovery, has morphed into a method to prolong life
  – Technology
  – Cure and management of much of cancer and heart disease
  – Patient’s Self Determination Act - 1990

• 21st Century............
  – Increased medical consideration and public awareness re: end of life care, and planning.
    • Futility vs QoL
Medical Beliefs/ Goals

• Medical focus to prolong life
• Death is Avoidable
• BUT... WE ARE MORTAL
  – Being Mortal, Atul Gawande
  – End of life planning
History of Advanced Directives
Medicolegal Ethical Issues

- Karen Ann Quinlan (1975-1985)
  - Ethics committees in hospitals, NH, hospices
  - Legal underpinnings of advance directive documents

- Nancy Cruzan (1983-1990)
  - Led states to formalize laws governing
    - Withhold or withdrawing life-sustaining treatments
    - Living wills
    - Healthcare proxies

- Patient’s Self Determination Act (1990)
  - Requires agencies receiving federal funds inform patients of right to complete an Advance Directive

- Terri Schiavo (1990-2005)
  - Feeding tube, right to die, court, government battles
Video about Nancy Cruzan

- https://youtu.be/mZO2te-sv3g
How We Die in the U.S.

• Between 60 and 70% of seriously ill patients will not be able to decide for themselves whether or not they want to limit treatments, including life support measures. This leaves these difficult decisions up to loved ones and family members.
End of Life in the U.S.

- 85% of people will experience one of these trajectories at the “end of life”
  - 20% Cancer
  - 25% Organ Failure
  - 40% neurodegenerative diseases/Frailty
- Average of 2-4 years of disability before death
Cancer Trajectory, Diagnosis to Death

Cancer

Time

Function

High

Low

dead
Dementia/Frailty Trajectory

Function

High

Low

Time

death
Why?- Our Role in Advanced Care Planning

Goal to maximize:

• Function
• Comfort
• Quality of life
• Family understanding
ANA position statement: Nurses’ Roles and Responsibilities in Providing Care and Support at the End of Life

Effective 2016

ANA Nurses’ Roles and Responsibilities in Providing Care and Support at the End of Life - 2016

• Provide comprehensive and compassionate palliative and EOL care
  – Support patient and family
• Recognize when death is near
  – communicate to family
• Alleviate symptoms
  – Pharm and non pharmacologically
• Collaborate with professionals to optimize patients’ comfort and families’ understanding and adaptation.
• Practice, Education, Research, Administration
Case: Jean

- 85 yo, married x 63 years, husband (age 88)
- Parkinson’s disease x 10+ years, slow decline
- ADLs-
  - needed help w/ toileting, hygiene, walker, eating w/ coughing
  - dependent IADLS,
- Falls, hospitalized twice - discharged within 2 days.
- Prolonged hospitalization for pneumonia, meds not given on time, deconditioned, decub from prolonged bedrest – determined to go home.
- Discharged with privately paid help at home, but care was very difficult,
- Acute confusion, admitted to hospital, ICU, ventilator, and died 2 days later.
- Family was shocked: did not realize she was so ill, frail
  - no advanced care planning, had not discussed her wishes with her,
  - surprised that no health professional counseled her re: advanced care planning
  - felt that if they had realized, they would have had a plan in place
AMA policy on End of Life Care

- **Opinion E-2.035 Futile Care**
  - Not ethically obligated to deliver care that will not have a reasonable chance of benefiting their patients.

- **Opinion E-2.037 Medical Futility in End-of-Life Care**
  - If care is futile—obligation to focus on comfort and closure

- **Opinion E-2.17 Quality of Life**
  - Treatment of seriously disabled newborns or of other persons who are severely disabled by injury or illness, the primary consideration should be what is best for the individual patient.

- **Opinion E-2.20 Withholding or Withdrawing Life-Sustaining Medical Treatment**
  - The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail.
ANA Recommended Tools

• Caringinfo.org- lists each state’s advanced directives.
• American Cancer society advanced directives info
• AARP advanced directives
• US Living Will Registry
  – Advance Directive Registration
  – Price $59.00
  – Ensure that your advance directive is available when you need it, wherever you are. Purchase two or more registrations and receive 10% off the entire order.
Barriers to EOL care

• U.S. health care system is ill designed to meet the needs for patients near the end of life and their families.

• The system
  – acute care aimed at curing disease,
  – not at providing the comfort care most people near the end of life prefer.

• The financial incentives built into the programs
  – not well coordinated
  – result is fragmented care that increases risk to patients and creates unavoidable burdens on them and their families.

• Educating Nurses in Excellent Palliative Care The End-of-Life Nursing Education Consortium (ELNEC)
Palliative and Advanced Care Planning

• Sooner the better
  • still able to make decisions
  • understands ramifications of choices

• Discuss at 1\textsuperscript{st} or 2\textsuperscript{nd} visit until documents are brought in or patient/family clearly understands and chooses not to complete.
Benefit of encouraging end of life conversations early in disease

- Decrease fear
- Empowers-Increase control
- Understand choices (antibiotics, ICU, Feeding tube)
- Create family consensus
- Decrease unnecessary or futile medical care
- Confidence health care provider understand patient’s and family’s GOAL
- Avoid crisis decision making
Advanced Care Planning - Conversation, a Process

• Initiate, make it routine, Normalize
• Assess knowledge, readiness, do they have documents-
  – Scan to EHR
• Decisions may need to be made for future care
• Quality of life that’s acceptable
• Goals? What? Who?
• Documents
• “Hope for the best, plan for the worst”
• Discuss with loved ones
Goals of Care

- Realistic goals
- What’s important?
- How do you want to spend your time?
- What is scary to you?
- Comfort care
National Health Care Decision Day
April 16

• Since 2007, exists to inspire, educate and empower the public and providers about the importance of advance care planning

In this world nothing can be said to be certain, except death and taxes.

(Benjamin Franklin)
Advanced Directives
Assessing Capacity

- Understand relevant information about the treatment choice
- Appreciate their health condition, treatment choices and consequences of their choices
- Make a choice and make the same choice relatively consistently
- Demonstrate a reasoning process to arrive at their choices

Applebaum, Grisso, 1988
Tool for Advanced Care planning

• The Conversation Project
  – http://theconversationproject.org/starter-kit/intro/

• 5 Wishes

• State specific Advanced Directive Forms
Advanced Directives: NC Medical Society

- Health Care Power of Attorney
- Advanced Directive for a Natural Death ("Living Will")
- An Advanced Directive for North Carolina – A Practical Form for All Adults
Legal Vs. Medical Documents
National Polst Paradigm

• An approach to end-of-life planning based on:
  – conversations between patients, loved ones, and health care professionals
  – designed to ensure that seriously ill or frail patients can
    • choose the treatments they want or do not want
    • their wishes are documented and honored
    • Last year of life
<table>
<thead>
<tr>
<th>CHARACTERISTICS</th>
<th>POLST</th>
<th>ADVANCE DIRECTIVES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>For the seriously ill</td>
<td>All adults</td>
</tr>
<tr>
<td>Time frame</td>
<td>Current care</td>
<td>Future care</td>
</tr>
<tr>
<td>Who completes the form</td>
<td>Health care professionals</td>
<td>Patients</td>
</tr>
<tr>
<td>Resulting form</td>
<td>Medical orders (POLST)</td>
<td>Advance directive</td>
</tr>
<tr>
<td>Health care agent or surrogate role</td>
<td>Can engage in discussion if patient lacks capacity</td>
<td>Cannot complete</td>
</tr>
<tr>
<td>Portability</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
</tr>
<tr>
<td>Periodic review</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
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</tbody>
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POLST = Physician Orders for Life-Sustaining Treatment
DNR and MOST

• DNR – Do not resuscitate
• MOST- Medical Orders for Scope of Treatment
  – Recommended for patients with serious illness or frailty, for whom a health care professional would not be surprised if they died within one year, should have a POLST (and in our state, MOST) Form
STOP
DO NOT Resuscitate

Effective Date: ____________
Expiration Date, if any

☐ Check box if no expiration

DO NOT RESUSCITATE ORDER

Patient's full name

In the event of cardiac and/or pulmonary arrest of the patient, efforts at cardiopulmonary resuscitation of the patient SHOULD NOT be initiated. This order does not affect other medically indicated and comfort care.

I have documented the basis for this order and the consent required by the NC General Statute 90-21.17(b) in the patient's records.

Signature of Attending Physician/Physician Assistant/Nurse Practitioner

Printed Name of Attending Physician

Address

City, State, Zip

Telephone Number (office)

Telephone Number (emergency)

Do Not Copy  Do Not Alter

DNR- Do Not Resuscitate
MOST- Medical Orders for Scope of Treatment
Documentation

• Advanced care planning discussion note
• Ask family to bring copy of Advanced directives to be scanned into medical record
• DNR, MOST
Billing for Advanced Care Planning (ACP)

- Face to face service between MD, NPP -and a patient, family member or surrogate for counseling and discussing advanced directives, with or without completing relevant legal forms (LW, HCPOA, DNR, MOST)
- CPT code 99497 – 16-30 minutes spent on ACP -$83.09
- CPT code 99498 each additional 30 minutes in addition to 99497
- Need to document
  - # of minutes spent
  - Documentation to support counseling and discussion
  
  - Per Dana Sheffield, compliance, Dana.Sheffield@unchealth.unc.edu
Palliative Care

• Pain Assessment – Pain AD

• Feeding tube discussion
  • Decisional aides
  • No efficacy
  • AGS Position statement

• Palliative care services
  – Disease specific recommendations
    • Websites, forums, support groups
Hospice Referrals

• Prognosis of 6 months or less if the disease follows its normal course of decline
• 44% of deaths are under hospice care
• Referral to hospice to discuss
  – Informational visit
  – Assessment visit
  – Hospice Eligibility criteria card:
    • http://geriatrics.uthscsa.edu/tools/Hospice_elegibility_card_Ross_and_Sanchez_Reilly_2008.pdf
REFERENCES


• D. Oliver (ed.), End of Life Care in Neurological Disease, 19

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