Talking About Death won't Kill you or Your Patients

Debbie A. Gunter RN,MSN,FNP-BC,ACHPN
Palliative Care Nurse Practitioner
Emory Healthcare
Atlanta, Georgia

- I have no financial relationships to disclose

Objectives

- 1. Describe the challenges of predicting disease trajectories for specific patients
- 2. Discuss the many roles of the NP when caring for the terminally ill patient
- 3. Describe a process for having difficult conversations regarding bad news, establishing goals of care, and or advance care planning.

How many of you are going to die?

- "Everyone knows they are going to die, but nobody believes it. If we did, we would do things differently…"(Morrie Schwartz)
- "The dignity we seek in dying must be found in the dignity with which we have lived our lives. The art of dying is the art of living…" (Dr. Sherwin Nuland)

How Would You Like to Die?

- When?
- Where?
- Circumstances?

Good Death

Is one possible?
What makes it good?
What makes it bad?

A Good Death

- The Institute of Medicine defines a good death as:
- "one that is free from avoidable distress and suffering for the patient,family and caregivers
- one that is in general accord with patients' and families' wishes
- and one that is reasonably consistent with clinical, cultural and ethical standards."

Death in the 1800's and early 1900's

- Life expectancy 50 yr
- At home
- Died from
  - Injury
  - Infection
- Comfort with "natural dying"
  - Stop eating and drinking
  - Body begins to slip into 'coma like state'
  - No IV's, few medications
- Doctor said "It's time"

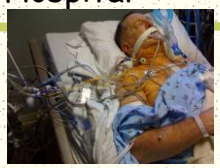
Dying in America: 1950s

- Introduction of antibiotics, improved surgical techniques and public health/ safety led to a decrease in infant, child, and maternal mortality
- 50% of deaths now occurred in hospital, family kept in waiting room
- The increase in medical technology led to changing expectations: focus on cure, not comfort.

Dying In America Now

- Advances in Medical Care
  - We now "cure" some previously fatal diseases, such as infections and childhood leukemia
  - Most advances in technology have not "cured" disease, but rather have prolonged the experience of living with chronic disease

50% of Americans Die in the Hospital



Dying at home




TV

- CPR survival on TV shows of House and Grays Anatomy – 70%
- Most deaths presented in TV/movies are rapid and dramatic.

Reality

- CPR survival < 13%
- 90% of us will die from a chronic disease, with repeat hospitalizations during last year of life
- In reality, only 10% of us will die suddenly from an acute event

Who is dying in the U.S.?

- Median age of death is 77 years.
- Among survivors to age 65, median age at death is 84 for women, and 80 for men.
- In the frail elderly, death follows a long period of progressive functional decline and loss of organ reserve accompanied by specific disease processes.

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Major causes of death in America - 2014

- Heart disease: 611,105
- Cancer: 584,881
- Chronic lower respiratory diseases: 149,205
- Accidents (unintentional injuries): 130,557
- Stroke (cerebrovascular diseases): 128,978
- Alzheimer's disease: 84,767
- Diabetes: 75,578
- Influenza and Pneumonia: 56,979
- Nephritis, nephrotic syndrome: 47,112
- Intentional self-harm (suicide): 41,149

Leading Causes of Death

- 50% are not cancer but are still NOT curable
  - Heart disease
  - Lung disease
  - Neurological disease – dementias, PD
  - Renal disease
- Who do you see in your practice??

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Should We Talk With Mrs. P?

81 y/o with systolic heart failure, severe peripheral vascular disease, a systolic blood pressure of 100, and shortness of breath with mild exertion.

She has had 3 hospitalizations in the last 6 months for HF exacerbations.

She is being treated appropriately with medications.

You are seeing her for F/U after hospitalization.

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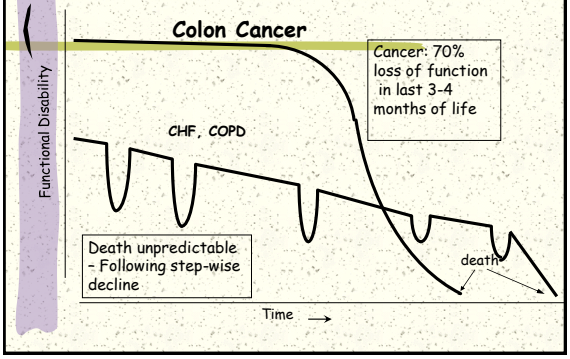
When Is It Appropriate To Begin Talking To Your Patients About *Dying*?

The patient has: a chronic life limiting illness <u>And:</u>

- Is progressively losing function and/or weight despite best medical therapy and/or
- Is requiring increasing medical resources with no improvement in quality of life and/or
- The patient has requested no further measures to reverse current or future medical problems (e.g. no antibiotics for the next pneumonia)

Illness Impact Trajectory



How Can You Move Forward ..

- Recognize who has a terminal illness!
  - This is the single most important issue in end-of-life care—unless you can recognize and name the process, there will be no timely transition away from curative or life-prolonging care, towards palliative care.
- Understanding disease trajectories can assist in determining when someone is dying.

Making Difficult Decisions

- *"Modern medicine may have made dying harder, but it has also given us the gift of time - the time to prepare, the time to heal family wounds, the time to bring psychological and spiritual closure.*
- *If we can take advantage of it, it has given us something unique in history - the time to tie up loose ends and orchestrate a death that is good." (Marilyn Webb, The Good Death)*

Role of the NP In terminal illness

- Healthcare provider
  - Any stage or type of the illness
    - Cancers
    - Non-cancers – heart failure, COPD, neurodegenerative diseases
- Educator
- Guide
- Support
- Sounding board

Approach To Terminal Illness

- What is the disease?
- Trajectory?
- Where is patient on this trajectory?
- Goals?
  - Patient's
  - Family's

When Should Goals Be Discussed?

- Routine outpatient visit, chronic life-limiting disease (optimal), but …
  - Difficult to schedule sufficient time for thorough discussion
  - Difficult to anticipate all possible scenarios
- Times of crisis
  - Worst possible time to make difficult decisions
  - Usually when the "big" decision are actually made

Potential Goals of Care

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement in function
- Prolong life
- Relief of suffering
- Quality of life
- Staying in control
- A good death
- Support for families and loved ones

Goals May Change Near the End of Life

- Some goals may take priority over others
- The shift in the focus of care
  - is gradual
  - is an expected part of the continuum of medical care
- Review goals with any change in
  - health/functional status (e.g. advancing illness)
  - setting of care
  - treatment preferences

Dying As A Taboo Topic

- Discussing Goals of Care will inevitably raise the issue of *dying*: why, when, how.
- Dying is a taboo subject for both the patient and provider.
- All forces work to avoid talking about dying, yet, it is central to a Goals of Care discussion.

How Do Goals Get Established?

- Healthcare directed
  - Important in life-threatening emergency situations
  - Risk of paternalism—imposition of practitioner's values without due consideration of patient/family values
- Patient-Family directed
  - Enhances autonomy but…loses importance of practitioner's recommendations based on knowledge/experience; may enhance family guilt when considering treatment limitation or withdrawal
- Shared decision making
  - Ideal process— working together with patient-family to arrive at goals based on patient values combined with physician recommendations.

Difficult Conversations

- **Importance**
  - **Most patients and families want to know what to expect**
  - **Strengthens NP – patient relationship**
  - **Fosters collaboration**
  - **Permits patients, families to plan and cope**

Difficult Conversations

- **Plan what you will say**
  - **Confirm medical facts**
  - **Don't delegate**
  - **Create a conducive environment**
  - **Allot adequate time**
    - **Prevent interruptions**
  - **Determine capacity for decision making**

Difficult Conversations

- What does the patient/family know?
  - Establish what the patient or family knows
  - Assess ability to comprehend new information at this time
  - Reschedule if unprepared

Difficult Conversations

- **How much do they want to know**
  - **People handle information differently**
    - **Individual preferences, cultural traditions, religious teachings, socioeconomic status**
    - **Developmental and maturity level**
  - **When family says "don't tell"**
    - **Ask the family:**
      - **Why not tell?**
      - **What are you afraid I will say"?**
      - **What are your/the enrollee's previous experiences?**

    Explain the benefits of knowing

Difficult Conversations

- **Promote the Dialogue**
  - **Determine previous experiences with same illness among friends/families**
  - **Avoid jargon, euphemisms**
  - **Use long periods of silence frequently**
  - **Check for understanding**
  - **Use and observe body language**

Getting At The Patient's "Voice"

- When the patient is not able to participate:
  - Bring a copy of their Advance Directive to the meeting
  - Ask the family: *"if your father were sitting here, what would he say"*

Managing Conflicts

- Remember, acceptance of dying is a *process*; it occurs at different times for different family members.
- Remember, a sudden illness or illness in a young person makes acceptance of dying more difficult for everyone.
- Remember, prior family conflicts, especially concerning alcohol, drugs or abusive relationships, make decisions very hard to achieve.

Common Reasons For Conflict?

- The Patient/Family
  - Lack of accurate information
  - Guilt/Fear/Anger
  - Grief—Time
  - Lack of trust
  - Cultural/Religious conflict
  - Dysfunctional family system

Difficult Conversations

- **Planning, follow-up**
  - **Plan for the next steps**
    - **Additional information, tests**
    - **Treat symptoms, referrals as needed**
  - **Discuss potential sources of support, inquire about needs and preferences**
  - **Affirm your continued support**
  - **Provide written information**

What is Advance Care Planning (ACP)

- Planning for future medical care in the event a patient is unable to make own decisions
- Should be updated regularly
- Values/goals are explored & documented
- Designate surrogate decision-maker
- It is a process, not an event
- Reduces confusion & conflict

Instruments Used in Advance Care Planning (ACP)

- Instructions for Medical Care
  - Living will
  - Verbal statements
  - Personal letter or value statement stating preferences
- Designation of decision maker
  - Health Care Proxy or Agent
  - Durable Power of Attorney for Health Care

Patient Barriers to Completion of Advance Directives

- Belief that HCPs should initiate discussions
- Procrastination and/or avoidance
- Apathy
- Belief that family should decide
- Family would be upset by the planning process
- Fear of burdening family members
- Discomfort with the topic
- Mistrust of the system

HCP Barriers to Advance Care Planning

- Belief that patients should initiate discussions
- Discomfort with the topic
- Time constraints
- Misunderstanding of ADs
- Timing of conversation
- Negative attitude

Fostering Advance Directive Discussions

- Make it routine
  - "This is something we talk about with all patients"
- Elicit important values
  - "What makes life worth living for you?"
  - "What makes life NOT worth living for you?"
- Address a limited number of issues
  - CPR, Artificial nutrition and hydration

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Life-Sustaining Treatments

- Resuscitation
- Elective intubation
- Surgery
- Dialysis
- Blood transfusions, blood products
- Diagnostic tests
- Artificial nutrition & hydration
- Antibiotics
- Other treatments
- Future hospital or ICU admissions

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Withdrawal vs Withholding of Life - Sustaining Treatments

- Legally, there is no difference between withdrawal vs withholding of life sustaining treatments
- However, psychological, emotional, or religious constraints may exist for family.

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Artificial Nutrition and Hydration

- States have different laws guiding care surrounding ANH
- Benefits vs burdens of ANH
- What are the goals of ANH?

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Common Concerns

- Legally required to "do everything?"
- Does withdrawal/withholding constitute euthanasia?
- Are you killing the patient when you remove a ventilator?
- Is the use of opioids to control symptoms at the end of life euthanasia?

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Consequences of Ignoring the Issue

- **Lack of trust and collaboration; dissatisfaction**
- **Increased desire for futile aggressive care**
- **Unnecessary physical, emotional, spiritual suffering**
- **Techniques**
  - **Commit to working together for best care possible**
  - **Understand and accommodate desires for more aggressive care, and use respectful negotiation when this is contraindicated or medically futile**
  - **Avoid complex medical jargon**

Communicating Prognosis

- Physicians/ NPs markedly over-estimate prognosis
- Accurate information helps patients/family cope and plan
- Offer a range or average for life expectancy
- Limits of prediction
  - Hope for the best, plan for the worst
  - Better sense over time
  - While feeling relatively well and thinking clearly, get affairs in order
- Reassure availability, whatever happens

Medicare Reimbursement for Advance Care Planning

- Effective January 1, 2016, Medicare will pay $86 for 30 minutes of ACP in a physician's office and will pay $80 for the same service in a hospital (CPT billing code 99497).
- In both settings, Medicare will pay up to $75 for 30 additional minutes of consultation (add-on CPT billing code 99498).
- Such counseling can take place during a senior's annual wellness visit or during a routine office visit and at various stages of health, always "at the discretion of the beneficiary."

Documentation Requirements

- A person designated to make decisions for the patient if the patient cannot speak for him or herself
- The types of medical care preferred
- The comfort level that is preferred (Required for Medicare Advantage only):

Patient consent for ACP performed as part of an annual wellness visit

How the patient prefers to be treated by others

What the patient wishes others to know

Adequate documentation also requires an indication of whether or not an advance directive or POLST (physician orders for life-sustaining treatment) document has been completed. -

The Journey – What Is Dying?

- I am standing on the sea shore, a ship sails in the morning breeze and starts for the ocean. She is an object of beauty and I stand watching her till at last she fades on the horizon and someone at my side says: "She is gone."
- Gone! Where? Gone from my sight—that is all.
- She is just as large in the masts, hull and spars as she was when I saw her, and just as able to bear her load of living freight to its destination.
- The diminished size and total loss of sight is in me, not in her, and just at the moment when someone at my side says, "She is gone" there are others who are watching her coming, and other voices take up a glad shout: "There she comes!" — and that is dying.

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