Caring for Frail Elders at the End of Life: A Roman Catholic Perspective

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Considering the Trajectory of Dying

- The next few slides are from the EPEC (Educating Physicians on End of Life Care)
- These slides and other EPEC materials are not to be reproduced without acknowledgment
- The slides illustrate the paths we take as we face the end of life: sudden death, an illness like cancer, or a protracted chronic illness like Alzheimer’s disease, severe heart failure, or emphysema/COPD

Objectives

- Describe three trajectories of dying and provide an example of each
- List common findings that are associated with frailty in the elderly
- Differentiate between acute and palliative care paradigms
- Develop a list of key questions in the assessment of the frail older person
...Objectives (cont.)

• Provide examples of appropriate and inappropriate interventions in the care of a frail older person
• Relate common barriers to good palliative care in older persons
• Explain Catholic Church teaching on the value of life and excessive medical interventions

End of life in America today

Modern health care

• Only a few cures
• Live much longer with chronic illness
• Dying process also prolonged

(from EPEC, “Gaps in End of Life Care”)

Protracted life-threatening illness

> 90%

• predictable steady decline with a relatively short “terminal” phase
  • cancer
• slow decline punctuated by periodic crises
  • CHF, emphysema, Alzheimer’s-type dementia

(from EPEC, “Gaps in End of Life Care”)
Sudden death, unexpected Cause

< 10%, MI, accident, etc

Steady decline, short terminal phase

Slow decline, periodic crises, sudden death

From EPEC, "Gaps in End of Life Care"
Two questions

• How many residents do you have who are dying?
• How many residents do you have that you would not be surprised if they die in the next year?
• Think about the diagnoses/events/conditions that make you answer differently to #2

What makes you not surprised?

• Recurrent hospitalizations
• Recent hip fracture with poor result in rehab
• Recent stroke
• Dementia with progressive functional decline
• CHF, emphysema

Trajectory of dying

• Pay attention to the inexorable downward slope, punctuated by acute crises with partial improvement
• Think about your residents who are gradually losing function
• Consider what you can and cannot do to help them
• Think a bit more about frailty...
Frailty and Caring for Older Persons: Objectives

- List the characteristics that define frailty in an older person
- Describe appropriate assessment and interventions in a frail older person
- Discuss hospice and palliative care, their similarities and differences
- Explain how an acute care paradigm may not be appropriate for the frail elder and give examples of appropriate palliative interventions

Frailty

- Easy to recognize, hard to define
- Not a diagnosis, but a description: Caused by multiple conditions
- Characterized by some or all of the following
  - weight loss
  - functional decline with assistance in ADL's
  - frequent falls
  - decline in cognitive status
  - development or non-healing of pressure sores

- What do you do?

Getting the paradigm right

- A paradigm is an example that serves to provide insight and guidance in similar situations
- As physicians, we learn a paradigm of acute care, mainly with hospitalized patients, that emphasizes aggressive therapy, brief interactions, and aims at cure
Caring for older persons...

- Age in and of itself may not be a helpful guide
- For some active old people, the acute care, cure oriented paradigm is appropriate
- For the frail older person, a palliative approach is likely more appropriate

Palliative care

- From the Latin *pallium*, meaning a cloak or a shelter
- Palliative care is NOT equivalent to hospice care
- One can combine palliative care with curative cure
- Palliative care addresses suffering in all its dimensions

Hospice and Palliative Care

- Hospice care is care directed at comfort and symptomatic relief for individuals who are clearly dying, usually with six months or less of life thought likely
- Palliative care is directed at suffering at any stage in any illness, can be combined with curative and other therapies, and seeks to limit distressing symptoms: physical, psychological, spiritual, social and familial.
- The next slide from EPEC shows how palliative care and hospice care relate
**Curative / remissive therapy**

Spectrum of Palliative Care...taken from EPEC

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**Suffering and pain**

- **Physical**: pain and symptom control
- **Psychological (Emotional /Mental)**: loneliness, anxiety, depression
- **Social**: isolation, loss of relationships, decreased ability to care for self
- **Spiritual**: uncertainty, why me?, guilt, fear
- **Familial**: what are the roles now?

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**Ethics and the Trajectory of Dying**

- Because we value life, we want our care to be appropriate and clinically excellent
- There are different interventions that are best depending on the person’s underlying clinical situation
- Hospice care is appropriate with those who have a short time to live, palliative care is appropriate for those persons we are continuing to intervene medically and treat, even if we know cure is not possible
The Ethics of Caring and Relieving Suffering

- Our ethical obligation is always to care, even when we cannot cure.
- That means assessing suffering and pain carefully and alleviating it.
- Efforts to alleviate suffering are not all medical or pharmacological; it includes spiritual care, a vibrant activities program, good social work, and attentive physical and occupational therapy services.

Assessing the frail elderly...

- Why is this person falling apart?
- *Primum non nocere*: Can the Physician diagnose and treat without causing more harm than good?
- Is medication causing the problem?
- What is the person’s nutritional status and are there appropriate interventions available?

Assessing the frail elderly...

- What social issues are affecting this resident?
- Are there spiritual concerns that need to be addressed?
- What is the family’s role? How involved are they?
...Assessing the frail elderly (cont.)

- What is the person’s functional status and could occupational or physical therapy be able to effect an improvement?
- What is the person’s mood/affect? Is depression and/or anxiety a part of the picture?

Things not to miss medically in assessing the frail older person...

- Hypo/hyperthyroidism
- Tuberculosis
- Severe anemia
- Subdural hematoma
- Electrolyte disturbance (often secondary to medication, poor po intake, etc.)
- Obvious malignancy
- Diabetes

Assessment

- History from person and caregiver, pay attention to rate of change, assess pain
- Physical exam: postural BP changes, pulse, temperature...etc.
- Neurologic exam, including mental status and assessment of mood
- Labs: CBC, CMP, TSH, U/A, PPD
- Radiology: CXR, maybe CT if falls
**OK, now what?**

- Probably have a ton of diagnoses
- May have several possible approaches
- Need to develop a care plan that recognizes the goals of the resident and/or surrogate, limits suffering, and looks to possible ways to improve function...and if changes are acute or treatment obvious, then move quickly...

*(in other words, you don’t treat TB, a TSH of 40, or a sodium of 138 with conversations, sympathy, or a hospice referral.)*

**Some specifics...**

- Have a rational medical regimen that limits side effects and maximizes comfort and function: Does the resident need analgesia? An antidepressant?
- Only obtain diagnostic testing if you will do something with the results
- Does this resident have an advanced directive? Approach resident/surrogate with a discussion about goals of care, not endless talk about specifics.

**...Some specifics (cont.)**

- Consider, especially with nursing home residents, resuscitation status and hospitalization status. How would resuscitation or hospitalization limit suffering?
- Be attentive to issues of feeding and hydration, but very cautious about use of feeding tubes
...Some specifics (cont.)

• Don’t do it all by yourself: ask the care plan team to:
  --- revisit the care plan does it provide care for the resident or is it answering a regulation.
  --- what other interventions can be considered with respect to all areas of comfort?

Some specifics: Is it time to prepare for death?

• Consider End of Life Care /Hospice Care
• Preparation for death is an essential part of Catholic health care
• Avoiding it is seriously wrong and creates needless suffering

• Next 4 slides are an overview of the barriers we will discuss in detail tomorrow
• Handout in your packet
### Potential Barriers to Good Palliative Care Care

- Lack of understanding on the part of staff, physicians, nursing, family, or resident
- Fear of regulations and rigid response to “cover” one’s self rather than looking to residents good
- Poor social environment in the facility
- Loneliness or family problems for the resident
- Failure to take responsibility for one’s own actions on the part of caregivers and misunderstandings/lack of knowledge about Church teaching
- What else would you list?

### Some potential barriers on the side of the resident

- Reversible illness
- Difficult family relationships
- Unrealistic expectations

### Some potential problems on the doctor side

- Not trained adequately in palliative care
- Not enough time to think
- Miserable reimbursement
- Can be easier to just treat
- Takes time to plan, advance directives, deal with family
- Uncertainty about prognosis
- Can be cynical, greedy, burned-out
Some potential barriers on the nursing home side

- Too little staff, perhaps of uncertain ability
- Asinine state regulations
- Fear of regulations leads to extraordinary rigidity and “endless” documentation creates behavior that does nothing for residents
- “Short Staffed”
- Low Reimbursement

Getting our perspective right...

- In the Catholic tradition, we have a rich heritage on facing the end of life
- Death is understood in the context of our faith
- Life on earth has inestimable value
- But we are called to eternal life with God

What’s Catholic about this?

- Natural law and revelation:Appealing to common sense and what we know from God’s self-communication
- We are very careful and concerned about the value of life
- Sometimes miss the point: we value life, not just longevity
- Catholic health care should be exemplary in caring for the frail older person at the end of life
Life on earth: a sacred reality but not an absolute value

- Correcting a misperception: It is not true that one must use aggressive treatment at all times to prolong life...
- John Paul II “Evangelium vitae”
  “...life on earth is not an ‘ultimate’ but a ‘penultimate’ reality; even so, it remains a sacred reality entrusted to us...”

Value of life in the Catholic tradition

- “Both the artificial extension of human life and the hastening of death, although they stem from different principles, conceal the same assumption: the conviction that life and death are realities entrusted to human beings to be disposed of at will. It must be made clear again that life is a gift to be responsibly led in God’s sight.”
  John Paul II
  Address at the Rennweg Hospice in Vienna
  June 21, 1998

3 ethical Dilemmas

- Feeding Tubes
- CPR in Frail Elders
- Recurrent Hospitalizations
Use of feeding tubes

- The Church teaches a presumption in favor of their use, not a requirement.
- There is a presumption in favor of CPR, too...but there are times one does not do it!
- Thus, I do not usually use feeding tubes in the end stages of chronic decline and illness...I do usually use feeding tubes with acute illness with swallowing dysfunction (Dr. Myles Sheehan)

References on feeding tube use


Rabeneck L, Wray NP, Petersen NJ. JGIM 1996; 11:287-293


CPR and hospitalization

- CPR not likely to work in setting of chronic decline and frail older person...will get a lot of broken ribs and then die.
- Recurrent hospitalizations (revolving door between nursing home and hospital) should lead to consideration of a DNH order and alternative care plan
Ethical dilemmas

- Many dilemmas are really about communication or education
- Some families are totally crazy, but not many
- If you don’t find out ahead of time about preferences, it’s your own fault
- Irrational fears about law suits can lead to over-treatment...law suits are something to worry about: rather be sued for good care than not be sued and hurting a patient by defensive over-treatment.

Summary...

- Frailty is a common condition among elderly
- Assessment requires a comprehensive approach
- A palliative framework may provide the best care in the absence of obviously treatable cause

...Summary

- Recognizing decline and likelihood of death is critical to developing good care plans
- There are fates worse than death, and we cause them by excessive medical care
- Catholic health care should be the model for the nation in excellent care of the frail elderly in home care, nursing home, and hospital settings
- In the Catholic tradition, overly aggressive medical interventions in the frail elderly may be seriously morally wrong