The Syndrome of Imminent Death:
Recognition & Management

Robert M. Taylor, MD
Medical Director, Center for Palliative Care
Associate Professor of Neurology
Associate Professor of Clinical Medicine
The Ohio State University Medical Center

Pre-Test

Objectives

- **At the end of the session, the participants will be able to:**
  - ✓ **Describe the key features of the syndrome of imminent death**
  - ✓ **Discuss the importance of recognizing the syndrome of imminent death in order to provide optimal care for patients & their families**
  - ✓ **Explain to families the rationale for providing or withholding certain treatments for imminently dying patients**

Pre-Test

- **What percentage of Americans die?**

Pre-Test

- What percentage of Americans die?
- What percentage of your patients will die?

An Exercise in Imagining

- You have lived a long & fulfilling life
- You accomplished everything you ever hoped for, personally & professionally
- Your family is well & prosperous
- You are at peace with yourself & the world

*Thanks to V. S. Periyakoil, JPM 11(5): 694; 2008

An Exercise in Imagining

- You have lived a long & fulfilling life
- You accomplished everything you ever hoped for, personally & professionally
- Your family is well & prosperous
- You are at peace with yourself & the world
- Imagine how you would want to die

*Thanks to V. S. Periyakoil, JPM 11(5): 694; 2008

Did your fantasy death include

- Dying while being coded?
- Dying in the ICU on a vent?
- Dying in the hospital?
- Dying in a nursing home?
- Dying in your own home?
- Dying with your family around you?

Randy Pausch interview with Diane Sawyer - ABC, April 2008

"Someone's going to push my family off a cliff pretty soon and I won't be there to catch them - and that breaks my heart.

But I have some time to sew some nets to cushion the fall and that seems like the best and highest use of my time.

So I can curl up in a ball and cry … or I can get to work on the nets."

"When I am dying, I am quite sure that the central issues for me will not be whether I am put on a ventilator, whether CPR is attempted when my heart stops, or whether I receive artificial feeding. . . Rather, my central concerns will be how to face death, how to bring my life to a close, and how best to help my family go on without me."

- John Hardwig, Philosopher (HCR)

Two deaths - one extreme

- 65 year old man, stage IV lung CA
- In ICU on ventilator & CVVHD
  - ✓ Full code, on pressors & triple ATB
- Family distress & dissension & unrealistic expectations
- Dies in cardiac arrest while being coded

Two deaths - the other extreme

- 42 year old man, stage IV melanoma
- At home, hospice for 2 months, DNR
- Death recognized as imminent
- In sunroom, family & friends around
- Minister at bedside, prays over him
- Dies quietly & peacefully as prayer ends

Paradigm Shift

- Recognizing imminent death requires
  - ✓ Redefining the goals of care
    - Assure patient comfort
    - Support the family
  - ✓ Changing the way you think about the patient & family
  - ✓ Changing the way you talk to patients & families
  - ✓ Changing the management of the patient
  - ✓ Increasing your focus on the family

What's the problem?

- Difficulty recognizing a patient is dying
- Fear of being wrong
- Reluctance to acknowledge patient is dying
- Failure to understand benefit of recognition of imminent death
- Failure to understand harms of not recognizing imminent death
- Wanting to "Do Everything"

Negative consequences of failure to diagnose dying

- Patient & family unaware of imminent death
- Conflicting messages from different doctors
- Loss of trust
- Inappropriate tests, treatment, resuscitation
- Patient dies with uncontrolled symptoms
- Death distressing and undignified
- Patient and family distressed & dissatisfied

Why conceptualize Imminent Death as a syndrome?

- "Syndrome" is a useful concept in medicine
  - ✓ A group of signs and symptoms that together are characteristic or indicative of a specific disease or other disorder (MSN Encarta)
- Examples of other syndromes:
  - ✓ Congestive Heart Failure
  - ✓ Acute Renal Failure
  - ✓ Delirium
  - ✓ Chronic Pain Syndrome

Syndrome of Imminent Death

EPERC Fast Fact #3

- Early stage
  - ✓ Bed bound
  - ✓ Loss of interest/ability to eat/drink
  - ✓ Increased time sleeping &/or delirium
- Middle stage
  - ✓ Obtundation
  - ✓ "Death rattle" - pooled secretions

Why conceptualize Imminent Death as a syndrome?

- Imminent Death is best conceptualized as a syndrome that should be treated in a standardized way
- Dying can be normal & natural
- "Normalize" the dying process
- Bad management of the dying process, when foreseeable, is bad medical care
- There is such a thing as a Good Death

Syndrome of Imminent Death

EPERC Fast Fact #3

- Late stage
  - ✓ Coma
  - ✓ Fever - often due to aspiration
  - ✓ Altered respiratory pattern - apnea, hyperpnea, irregular
  - ✓ Mottled extremities

Syndrome of Imminent Death

EPERC Fast Fact #3

- Time course to traverse stages can range from less than 24 hours to as long as 14 days or more
- Explain to family that patient is dying
  - ✓ Discuss with health care team also
- Write in chart: "Patient is dying"
  - ✓ Not: "Prognosis is poor" etc.

Syndrome of Imminent Death

EPERC Fast Fact #3

- Treatment
  - ✓ Confirm primary goals
    - Assure patient comfort
    - Support family
  - ✓ Recommend stopping non-comfort measures
  - ✓ Treat symptoms as they arise
    - Secretions, delirium, dyspnea, pain, others
  - ✓ Provide excellent mouth & skin care
  - ✓ Provide daily counseling & support to family

Syndrome of Imminent Death

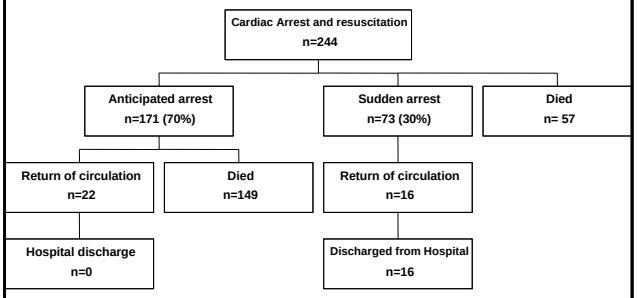
EPERC Fast Fact #3

- Address common family concerns:
  - ✓ Is he/she in pain? How do we know?
  - ✓ Are we starving him/her to death?
  - ✓ What should we expect? How much time?
  - ✓ Should I/we stay by the bedside?
  - ✓ Can he/she hear what we are saying?
  - ✓ What do we do after death?

Resuscitation

- Outcomes of in-hospital arrest
  - ✓ About 20-30% survive to leave hospital
  - ✓ Outcomes in specific populations are much lower: advanced CA, sepsis, renal failure
  - ✓ Television sends a different message
    - Diem et al (NEJM 334: 1578; 1996) watched ER, Chicago Hope, Rescue 911 (1994-5 season)
    - CPR occurred 60 times in 97 shows
    - 67% survived to hospital discharge

Resuscitation in cancer patients
Ewer et al, Cancer 92(7): 1905; 2001



Discussing Resuscitation

- **"Unfortunately, your disease is terminal and will soon cause your death. When that happens, your heart or breathing will stop. Attempts to resuscitate you will almost certainly fail. I recommend that, at that time, we focus on assuring your comfort and allow you to die peacefully & naturally. Do you agree?"**

Resuscitation is NOT appropriate for dying patients

- **Emphasize that the patient is dying**
- **Emphasize cardiac arrest is the mechanism of death, not cause of death**
- **Say "Attempt Resuscitation"**
- **Emphasize outcomes, negative effects**
- **Emphasize benefits of comfort care**

Fluids & Nutrition

- **Patients who are dying tend to stop eating & drinking - this is natural**
  - ✓ **Lose their appetites & become less alert**
  - ✓ **Lose the capacity to swallow**
- **Fluids & nutrition do not provide benefit**
- **More likely to be harmful**
  - ✓ **Especially with renal failure**
- **Dehydration contributes to comfort**

Level of consciousness

- Becoming less alert is part of the normal dying process
  - ✓ Occasional “lucid intervals” occur
- Reassure families that it is not “the medicine” that is making the patient drowsy or comatose
- Encourage families to continue to talk to the patient

Treating delirium

- Delirium is common and normal
  - ✓ Explain to family that this is normal
  - ✓ Rare to discover reversible cause
  - ✓ Limited efforts may be appropriate
- Use neuroleptics to treat delirium
  - ✓ Sublingual haloperidol usually effective
- Benzodiazepines for sedation w/caution
  - ✓ Usually in addition to neuroleptics

Treating pain & dyspnea

- Do NOT automatically start a morphine drip - rarely necessary for comfort
- Use opioids for pain or dyspnea
  - ✓ PRN initially - titrate to comfort
  - ✓ ATC or drip if previously required or if using frequent PRN doses
- Use anitcholinergics for secretions
- ALL available in sublingual forms

Palliative sedation

- Palliative sedation (PS) consists of sedating a dying patient to the point of unconsciousness to relieve one or more symptoms that are intractable and unrelieved despite aggressive symptom-specific treatments
- Typically, artificial hydration and nutrition are withheld, as they no longer offer any benefit to the patient and may cause adverse effects

Palliative sedation

- **Because PS is used mostly for patients who are imminently dying & suffering from terminal delirium or other symptoms, it is unlikely that PS shortens the patient's life in most cases**
- **However, in some cases, PS probably does shorten survival & this is difficult to predict or assess**

The Principle of Double Effect

- **Therefore aggressive comfort care, including palliative sedation, is ethical because:**
  - ✓ **Comfort & sedation are not unethical**
  - ✓ **Although these measures may hasten death, death is not primarily intended and comfort cannot be achieved without this risk**
  - ✓ **Comfort is achieved as a direct result of comfort measures and not by means of death**
  - ✓ **For an imminently dying patient, comfort is more important than prolonging life**

The Principle of Double Effect

- **An action which has both a good effect and a bad effect is ETHICAL if:**
  - ✓ **The act itself is not unethical**
  - ✓ **The good effect is primarily intended whereas the bad effect, though foreseeable, is not primarily intended and there is no alternative of achieving the good effect while avoiding the bad effect**
  - ✓ **The good effect is not achieved by means of the bad effect**
  - ✓ **The good effect is sufficiently desirable to compensate for allowing the bad effect**

Family Support

- **Keep nurses in the loop - they are on the front line with families**
- **Involve social workers & PCRMs for support of families & discharge planning**
- **Offer chaplain services to ALL families**
- **Mental Health nurses & psychologists may provide additional support**
- **Consider hospice referral**
- **Don't forget bereavement**

Care of the Dying

- **Too many patients die an uncomfortable death with uncontrolled symptoms**
- **Diagnosing imminent death is an important clinical skill we should all cultivate**
- **For a dying patient the primary goals are**
  - ✓ **To assure a comfortable death**
  - ✓ **To provide optimal care & support for the family**
- **Improving care of the dying requires education of all health care professionals**