American Academy of
Hospice and Palliative Medicine

ASSESSMENT AND CARE OF THE DYING PATIENT

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AAHPM Intensive Board Review Course

Care of the Imminently Dying

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Disclosure Information

Daniel Maison, MD FAAHPM

Has no relevant financial relationships to disclose.

Scope of the Problem

- 20% of us will die suddenly
  - Sudden Death
  - Acute Illness/Trauma
- 80% of us will die from a chronic illness
  - Heart Disease
  - Cancer
  - COPD
  - Dementia

Why is knowing how to care for these patients so important?

- Many of our colleagues do not know how
- May be when we are called in
  - We may only have hours to do our work
- Many commonly experienced symptoms can be incredibly challenging and distressing for patients and their families

Common things happen commonly

- Much of what we do in this phase of life is educating families
- Helping them understand what to expect and understand what usually happens can be tremendously helpful in their coping at this difficult time
- Give them the tools to anticipate what they might see and experience

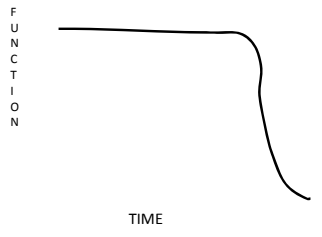
Good Summary

- Clinical Practice Guidelines for Quality Palliative Care (Second Addition) for the National Consensus Project For Quality Palliative Care
- Domain 7: Care Of The Imminently Dying Patient

Signs of Impending Death

- Cancer (Trajectory 1)
  - Bedbound
  - Increasing somnolence
  - Little po intake
- CHF (Trajectory 2)
  - No identifiable reversible precipitant
  - No response to diuretics, inotropes, etc.
  - Deteriorating renal function
- Dementia or "brain failure" (Trajectory 3 or 4)
  - Weight loss
  - Repeated admissions for infections
  - "Skin failure" – decubitus ulcers, etc.

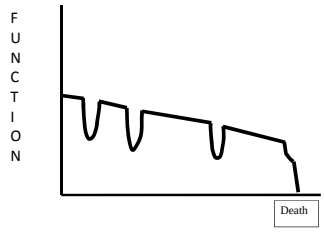
Trajectory 1 – Short decline



- Function preserved until late in disease
- Some cancers, ALS
- Of the patterns, tends to be the most predictable
- "Fall off a cliff"

From Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age, by J Lynn and DM Adamson, 2003, Santa Monica, CA: The RAND Corporation. © 2003 by The RAND Corporation. Reproduced with permission.

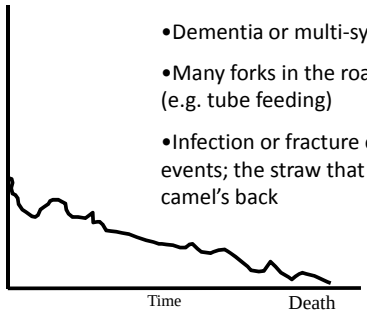
Trajectory 2
Chronic with Exacerbations



- Typical of COPD, CHF, end stage liver and HIV diseases
- Prognosis challenging
- "But they got better last time"

From Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age, by J Lynn and DM Adamson, 2003, Santa Monica, CA: The RAND Corporation. © 2003 by The RAND Corporation. Reproduced with permission.

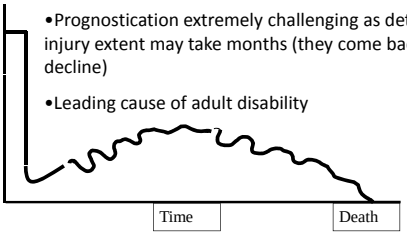
Trajectory 3
Progressive Deterioration



- Dementia or multi-system failures
- Many forks in the road over time (e.g. tube feeding)
- Infection or fracture often terminal events; the straw that breaks the camel's back

Trajectory 4
Sudden Neurological impairment

- Typical of stroke or traumatic or hypoxic brain injury
- Death can occur at acute stage or if treatment withdrawn
- Prognostication extremely challenging as determining injury extent may take months (they come back some, then decline)
- Leading cause of adult disability



Remember death is rarely perceived as routine by family

- Much of what you will be doing is education families (and staff) on what to expect and what we will be doing to ensure comfort
- Every change may be perceived as an emergency
- Expected changes in
  - Level of Consciousness
  - Urine Output
  - Secretions (e.g. "Death Rattle")

Routine Management: Constitutional

- Asthenia
- Fatigue
- Autonomic Dysregulation

Routine Management: HEENT

- Dry eyes
- Dry mouth
- Pooled oral secretions
  - Positioning
  - Suctioning
  - Education

Routine Management: Gastrointestinal

- Dysgeusia
- Dysphagia/Odynophagia
- Anorexia
- Loose stools/Diarrhea
- Constipation

Routine Management: Cardiovascular

- Hypotension/Hypertension
- Arrhythmias
- Congestive heart failure
- Cool extremities, decreased urine output

Routine Management: Pulmonary

- Increased secretions
  - Medications
    - Anticholinergics
- Pulmonary edema
  - Cardiogenic
  - Non-cardiogenic
- Bronchospasm
- Dyspnea versus Tachypnea

Routine Management: CNS

- Cognitive Failure
  - Somnolence
  - Confusion
  - Hypoactive delirium
- Seizures
  - Is patient on a medication they will not be able to take close to death?

Routine Management: Skin

- Mottling
- Skin Breakdown
- Ostomy management
- Wound management
  - Dressing change
  - Management of odor etc.

And when things don't go as planned?

- Do your best to expect the unexpected
- Ask the whole team, "what do you think might go wrong?"
- Established protocols for acute crises
- The last hours will be what the family remembers (often for years to come)

Some things to anticipate

- Patient will lose the ability to take orals
  - Do you have a back-up plan?
    - Sublingual
    - Suppositories
    - Subcutaneous
    - Intravenous
    - Transdermal (may not be reliable)

What Could Go Wrong?
Cardiopulmonary

- Acute dyspnea
  - –Pulmonary embolus
  - –Bronchospasm
  - –Congestive heart failure
  - –Pulmonary hemorrhage

What Could Go Wrong?
Cardiopulmonary

- Ischemic chest pain
  - –Acute coronary syndrome
  - –Myocardial infarction
- Defibrillator malfunction

What Could Go Wrong?
Central Nervous System

- Severe anxiety or panic attacks
- Seizures
- Agitated Delirium

What Could Go Wrong?
Gastrointestinal

- Bowel Obstruction
- Intractable Nausea and Vomiting
- Hemorrhage

What Could Go Wrong?
Family and Caregivers

- Anxiety
- Depression and suicide risk
- Complicated grief
- Spiritual crisis

Time course towards the end

- Depending on the patient, the pace of change can vary significantly
- There are recognized patterns of decline
- Again, knowledge is power and helping patients and families understand what can happen is often reassuring as things progress
- "How long do I have?"

Altered states of consciousness

- **Delirium** – acute onset, often fluctuating syndrome of disordered cognition and attention with disturbances of behavior and perception.
- **Coma** – state of being totally unaware of self and surroundings and inability to respond meaningfully to external stimuli.

Vegetative State

- **Vegetative state** –complete unawareness of self and environment but able to breathe spontaneously, maintain stable circulation, and eye closure cycles that may simulate sleep and waking.
  - **Persistent vegetative state** – present one month after injury
  - **Permanent vegetative state** – present 12 months or longer

Brain Death

- Irreversible cessation of all functions of the entire brain including the brainstem.
- Diagnosis requires:
  - apneic coma due to irreversible structural brain damage,
  - clinical tests that show no pupillary, corneal, vestibular, motor, gag or respiratory reflexes, and
  - Absence of hypothermia $\leq$35° C or any possibility of the coma being a result of
    - Sedatives, poison, neuromuscular blockers, metabolic or endocrine disturbance, or
    - Profound disturbance of electrolytes, glucose, or acid-base balance.

Conclusions

- Effective care of the imminently dying is a critical component of Palliative Medicine
- Anticipate the expected and communicate this to families
- Do your best to anticipate the unexpected and have a plan

THANK YOU