Navigating Sickness & Dying:

What happens to the body as someone is dying?

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Situation

- You've just been called to come to the hospital where a family is trying to make decisions about a loved one who is very ill. The doctors have told them he is dying. They want you to help them make decisions. Questions they have include:
  - Should they agree not to resuscitate?
  - He's not eating.
    - Should they ask for a feeding tube?

    OR
    - Should they stop current artificial nutrition/hydration?
  - How do we really know he's dying?

Objectives

1. Provide sample questions about disease progression, symptom management and benefit vs burden of certain treatments to assist you in these situations
2. Explore the difference between hospice & palliative care – and how these specialists can help
3. Review the management of pain and other symptoms common at the end of life
4. Consider a disease example to highlight progressive illness and nutritional issues
5. Explore disease progression and the imminently dying phase
6. Apply information to/review the questions

Questions: Disease Progression

1. What information is important to know about this illness and what will likely happen to over time?
   - What can be expected during the course of the illness in the coming weeks, months, years…

Examples: Dementia, heart disease, cancer

Questions: Disease Progression

2. How will we know when the person is in the terminal stages of the disease?
   - Weeks to months
   - Hours to days
   - Imminent

Questions: Symptoms

3. What symptoms will the person likely have?
   - Can anything be done for the symptom(s)?
   - Talk about your concerns

Questions: Symptoms

4. How are the different organ systems working?
   - Gut/GI tract
     - Can food be absorbed?
     - If the answer is NO – will it/can it get better?
   - Kidneys
     - Are they working?
     - If the answer is NO – will they/can they get better?

Questions: Resuscitation

5. Would attempts at resuscitation be successful?
   - If not, please explain why

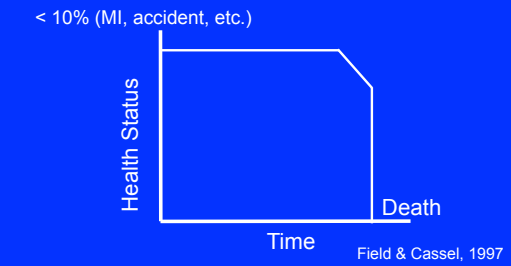
Questions: Palliative Care

6. Ask if there is a palliative care service available

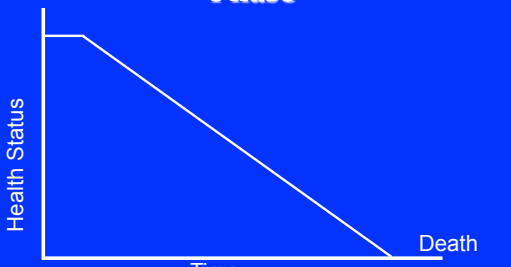
Cause of Death
Demographic and Social Trends

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infection	Chronic Illness
Average Life Expectancy	50	77.8
Site of Death	Home	Institution
Caregiver	Family	Strangers Health Care Providers
Disease Trajectory	Relatively Short	Prolonged

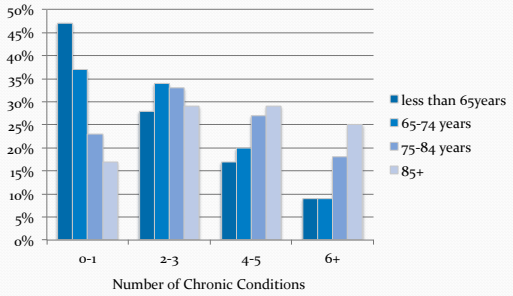
Illness/Dying Trajectories Sudden Death, Unexpected Cause

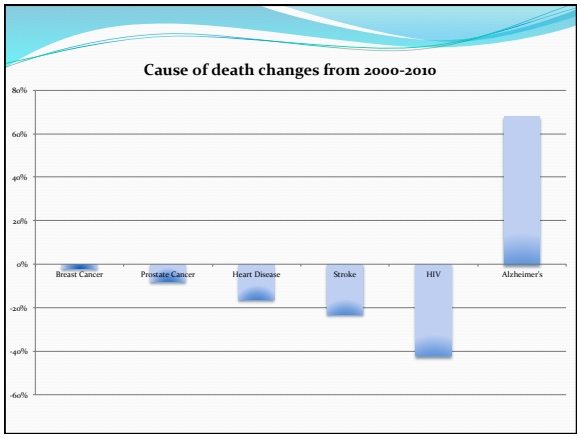


Illness/Dying Trajectories Steady Decline, Short Terminal Phase

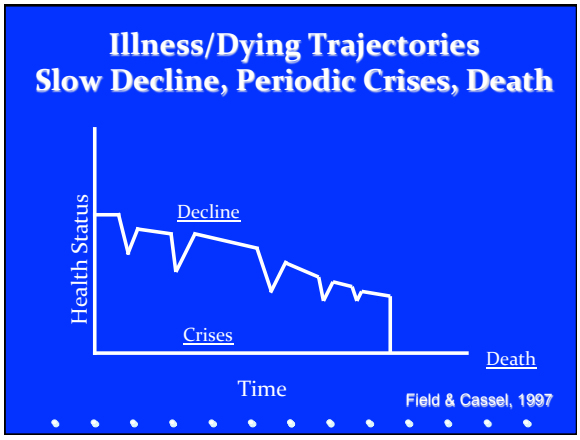


Multiple Chronic Conditions Increase with Age

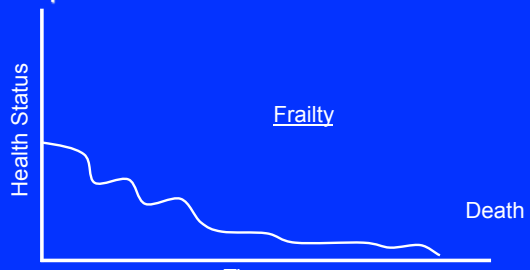




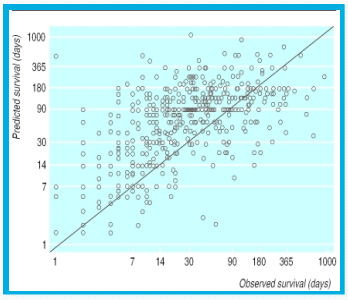
Illness/Dying Trajectories Slow Decline, Periodic Crises, Death



Illness/Dying Trajectories Lingering, Expected Death



Prognostication: Predicted Survival Days in Terminally Ill Patients



Predicted versus observed survival in 468 terminally ill hospice patients.

Diagonal line = perfect prediction

Above = survival overestimated

Below = survival underestimated

Christakis & Lamont, 2000

What is Palliative Care?

- Palliative care is specialized medical care for people with serious illness.
- Care is focused on providing patients with relief from symptoms, pain, and stress of a serious illness – whatever the diagnosis.

2011 Public Opinion Research on Palliative Care
www.capc.org

What is Palliative Care?

- Palliative care is provided by an interdisciplinary team who work with a patient's other doctors to provide and extra layer of support.
  - Doctor, nurse, social worker, pharmacist, chaplain/clergy
- Focus is on the patient, their family and other supports.
  - Cannot underestimate the impact on those closest to the patient
- Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

2011 Public Opinion Research on Palliative Care
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How Does Palliative Care Differ from Hospice?

Hospice care	Provides palliative care for those in the last weeks to months of life.
Non-hospice palliative care	Appropriate at any point in a serious illness. It can be provided at the same time as life-prolonging treatment.

Myths

- Accessing Hospice & Palliative Care
  - Means "giving up"
  - The person has to stop all treatments
  - Medications used to ease symptoms of the dying will kill the person:
    - Morphinophobia

Palliative Care aims to improve care in 3 domains

1. Attend to physical, emotional and spiritual suffering
2. Improve communication and decision-making
3. Coordinate continuity of care across settings

Case 1: Pain & Symptom Management

"God whispers to us in our pleasures, speaks to us in our conscience, but shouts in our pains; It is his megaphone to rouse a deaf world..."

C.S. Lewis, *The Problem of Pain*

Case Source: Meier & Brawley 2011, *JCO; 29(20):2750-2752.*

What is Pain?

- A complex constellation of unpleasant sensory, perceptual and emotional experiences
- Associated with physical, psychological, emotional and behavioral responses.
- It tells you something is wrong, serves a purpose

Barriers to Pain Relief

Health Care Professionals

- Inadequate assessment of pain and pain relief
- Lack of understanding of the pathophysiology of pain and clinical pharmacology of analgesics
- Lack of knowledge of other methods to control pain
  - drugs other than narcotics/opioids,
  - neurosurgical procedures
  - complimentary therapies
- Not understanding the difference between physical dependence and addiction.

Barriers to Pain Relief

Patients and Family Members

- Lack of awareness that pain can be managed
- Fear that taking narcotics will lead to addiction.
- Fear that use of analgesics will lead to confusion, disorientation and/or personality changes.
- Failure to report pain: the "good patient"
- Not distracting physicians from treating the disease.

Physiological Effects of Pain

Physiologic Effect	Results
Increased catabolic demands	Poor healing, weakness, muscle breakdown, debility
Decreased limb movement	Increased risk of clot formation (in limbs, lungs, etc.). Can be life-threatening
Respiratory effects	Shallow and/or rapid breathing, cough suppression, increased risk of pneumonia and poor oxygenation
Increased sodium and water retention	Causes generalized swelling; organ impairment, impaired function/mobility
Decreased gastrointestinal motility	Contributes to nausea, vomiting, constipation
Vital signs	Increased heart rate & blood pressure
Immunologic: decreased natural killer T cells	Reduces the body's ability to fight tumors and infections

Psychological Effects of Pain

- Anxiety and depression
- Sleep deprivation
- Inability to concentrate or address complex concerns
- Existential suffering

Terms

Term	Definition
Tolerance	A state of adaptation: exposure to a drug induces changes that result in decrease of one or more of the drug's effects
Physiological Dependence	A state of adaptation: class-specific withdrawal syndrome produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug
Psychological Dependence (Addiction)	A primary, chronic, neurobiological disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. Behaviors include 1 or > of the following: • impaired control over drug use, • compulsive use, • continued use despite harm, and • craving.

Principle of Double Effect

Differentiates between providing analgesic medications with the *intent* to relieve pain that might inadvertently hasten death vs providing medication to *intentionally* cause death.

1. The act itself must be morally good or at least indifferent.
2. The agent may not positively will the bad effect but may merely permit it.
3. The good effect must flow from the action at least as immediately (causality, though not necessarily time) as the bad effect.
3. The good effect must be sufficiently desirable to compensate for the allowing of the bad effect.

Principle of Double Effect

- Hastening death:
  - "Start low and go slow"
  - Increase (or decrease) to effect or intolerable side effects
    - Expertise is critical. Not all health providers posses it!
  - Consider physiologic effects of unrelieved pain on the heart, lungs, immune system and functional status
    - Unrelieved pain can impact survival
  - "There will always be a last dose of opioid" (Portenoy et al., 2006).

Common Non-pain Symptoms in Advanced Illness

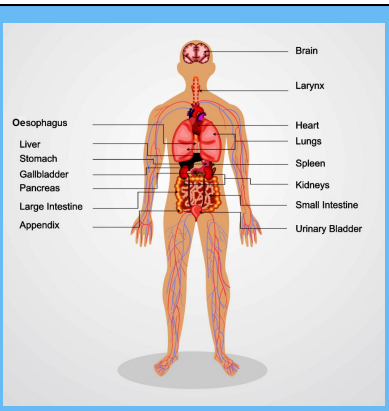
General	Weakness Fatigue Wounds Sleep Disorders Swelling of arms/legs
Respiratory	Difficulty breathing, breathlessness Cough
Gastrointestinal	Anorexia Constipation Diarrhea Nausea/vomiting
Psychological	Depression Anxiety Delirium/agitation/confusion

Disease Progression

Disease Progression

Issues to consider:

- What is the illness that the individual will die from?
- The natural course of the disease/condition?
- What other illnesses or conditions impact this primary condition?

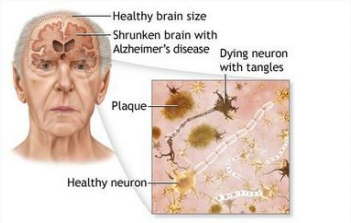


Disease Example: Dementia

- Dementia is an acquired syndrome that causes progressive loss of intellectual abilities:
  - Memory
  - Language (aphasia)
  - Capacity to use tools (apraxia)
  - Capacity to recognize objects (agnosia)
  - Planning and thinking in abstract terms (executive function)

Main Types of **Progressive** (Irreversible) Dementia

- *Alzheimer's Disease*
- *Dementia with Lewy Bodies*
- *Vascular Dementia*
- *Fronto-temporal Dementia*



Stages of Dementia

"Reverse development": most complex functions lost first

- Early stages:
  - may see differences in symptoms, behaviors
- In severe/terminal stages:
  - More similarities

Stages

Stage	Characteristics
Mild	• Memory problems • Spatial disorientation • Personality changes
Moderate	• Language difficulties • Unable to use tools/utensils • Confusion (may lead to agitation) • May have sleep deprivation
Severe	• Further progression of cognitive deficits, impaired comprehension • No longer recognizes need for basic daily functions (e.g. bathing, toileting, eating) • May resist care
Terminal	• Mute or unable to have meaningful verbal communication • May not be able to maintain eye contact

Functional Decline in Each Stage

Stage	Characteristics
Mild	Gradual decline in ability to perform ADLs
Moderate	Needing more assistance and reminders with basic ADLs May not be able to use utensils but may still be able to feed self Finger foods helpful
Severe	Development of motor difficulties Can't feed self Difficulty walking - Unsteady gait - Increased fall risk Incontinence starts
Terminal	Unable to walk, even with assistance Develops swallowing difficulties - Choking on food/liquids - Increased risk of aspiration of food, fluid, nasopharyngeal secretions

Common Complications: Infection

- Most common sites:
  - Urinary tract
  - Upper or lower respiratory tract
  - Skin
  - Subcutaneous tissue
  - GI tract
  - Eyes

NOTE:
Generalized infections are the most common cause of death

Brochopneumonia: cause of death in ~ 60% of Alzheimer's patients

Common Complications: Infections (continued)

- **Cause:** Increased susceptibility to infection due to
  - Changes in immune function
  - Incontinence
  - Decreased mobility
  - Aspiration – due to progressive neurologic changes

Common Complications: Malnutrition

- Individuals with dementia often lose weight
- Weight loss may be a presenting symptom (before diagnosis)
- Weight loss may be due to decreased intake or increased energy expenditure

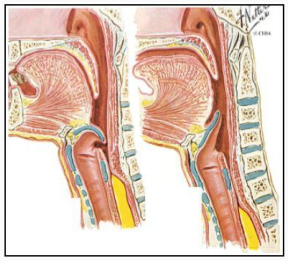
Weight Loss

- Increased energy expenditure
  - Wandering, restlessness
  - Rapid pacing (increases energy expenditure by ~ 1600 kcal/ day)
  - Increasingly active even if bed-bound
    - may have to increase calories to maintain body wgt
  - Parkinson's: muscle rigidity increases energy expenditure
- Large muscle atrophy: advanced stages

Weight Loss

- Decreased intake
  - Forget to prepare/eat food
  - Visual/spatial problems – not recognizing food
  - Decreased appetite
  - Depression
  - Unable to feed self
  - Swallowing difficulties

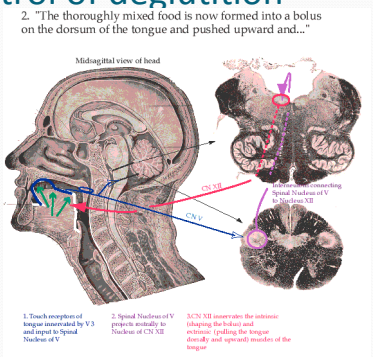
Swallowing

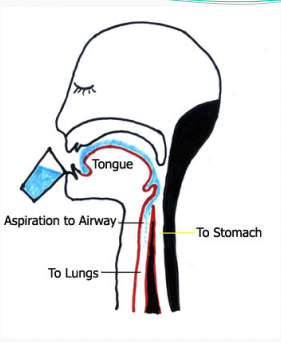


Swallowing involves the coordinated activity of the tongue, soft palate, pharynx, esophagus and 22 separate muscle groups

Control of deglutition

2. "The thoroughly mixed food is now formed into a bolus on the dorsum of the tongue and pushed upward and..."





Cachexia

- "Wasting" in some illnesses
  - A complex, involuntary, ongoing loss of body weight **even when a patient has an appetite and has an adequate intake**
- Cause: Underlying chronic inflammation, and complex metabolic and neuro-hormonal imbalances
- Result: effects on metabolism causing loss of muscle with or without loss of fat mass.
- Prominent features: weight loss in adults
  growth failure in children

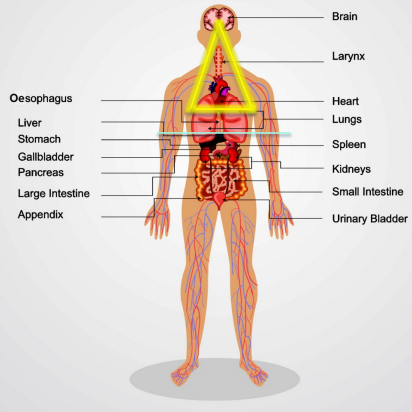
Cachexia (continued)

- Differentiated from starvation, age-related loss of muscle mass (seen in the elderly), primary depression, malabsorption and hyperthyroidism
  - Loss of appetite (anorexia) is associated with loss of fat, or adipose tissue.
  - In cachexia there is a loss of skeletal muscle with or without the loss of fat.
- Weight loss is rarely reversed by the addition of nutritional supplements or increased intake.
- In later stages, the focus shifts to relief of associated symptoms and management of the individual/family psychological impact of wasting.

The Dying Patient

What happens as the body approaches death

- The body systems work in harmony with one another.
- As the body dies, different organ systems start to not work as well, or fail all together
- The body focuses on preserving the
  - Brain
  - Heart
  - Lungs



Weeks to Months
1-3 months before death

- Increase in dozing or sleeping
- May be less interested in food
- Change in protein metabolism; inflammation (Cachexia)
- May show less interest in activities he/she once enjoyed
- May not want to engage as much with others
- Less verbal (adult); possibly more verbal if a child

Days to Weeks
1 – 2 weeks before death

- May see increase in symptoms
- Changes in blood pressure, heart rate, respiratory rate
- Continued loss of appetite and decrease in thirst
- Difficulty taking medicines by mouth
- Less urine, fewer bowel movements (unless diarrhea)
- Change in sleeping pattern
- Overwhelming fatigue
- May have congested breathing
- Hallucinations: visual or hearing

Hours to Days
Identifying the "Actively Dying" Phase

General signs & symptoms

- Progressive weakness & fatigue
- Functional decline: Bed-bound; unable to feed or tend to basic self needs
- Talking about "going home" or similar themes
- Hallucinations: visual, hearing
- Confusion: delirium, restlessness, agitation, coma
- Wounds

The "Actively Dying" Phase

GI Tract/Urinary tract

- Lack of appetite/not hungry
- Wasting (advanced cachexia)
- No change in nutritional status despite adequate supplements (may see swelling; "leaky vessels/cells")
- Constipation/diarrhea
- Nausea/vomiting
- Incontinent of urine or unable to pass urine
- Smaller amount of urine (or no urine)

The "Actively Dying" Phase

Neurological

- Sleeping most of the time
- Difficulty swallowing
- Short attention span; not sure of time
- Not able to close eyes
- Seizures (with some illnesses)

The "Actively Dying" Phase

Heart & Lung

- Lower blood pressure (not related to dehydration)
- Dropping blood pressure with faster, weak pulse
- Changes in breathing: rate or pattern
- Feeling of breathlessness (relieved by opioids)
- Noisy breathing (unable to clear saliva, other)
- Cooling of arms & legs: changes in circulation (hands, feet, shins)

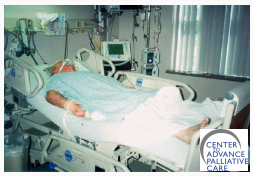
The "Actively Dying" Phase

Psychological

- Anxiety
- Depression
- Delirium
- Agitation
- Restlessness
- Confusion

Spiritual Issues/psychological distress

The Dying Phase: Decisionmaking



Pain and Symptom Management

- Consider
  - Impact of pain and other symptoms on survival
  - Recognize and attend to the distress of the individual as well as the family observing/coping with symptoms
  - Consider involvement of experts: pain/palliative care expertise

Resuscitation

Cardio-Pulmonary Resuscitation & use of ventilators

- Incredible life- saving medical advances
- Not recommended for dying patients

Nutrition: Ethical and Religious Directives for Catholic Health Care Services

- Part Five, Directive 58
  - In principle, there is an obligation to provide patients with food & water, including medically assisted and nutrition for those who cannot take food orally…
  - …Medically assisted nutrition and hydration become morally optional when
    - they cannot reasonably be expected to prolong life or
    - when they would be excessively burdensome for the patient or
    - would cause significant physical complications in the use of the means employed

Artificial Nutrition & Hydration (ANH)

- As organ systems fail in the imminently dying person, continuing or starting ANH may pose an increased risk of worsening symptoms
  - respiratory congestion, swelling, nausea/vomiting/diarrhea, wounds, and other symptoms
- Trial:
  - Hydration may help with some symptoms; stop if symptoms worsen or lung congestion increases
  - Unless clearly not advisable, trial with a temporary tube (through nose) for feeds if there is a question of benefit. Discontinue if symptoms worsen.
- Allow for oral fluids as desired
- Keep mouth from getting dry

Questions: Disease Progression

1. What can be expected in the coming (weeks, months, years)

2. How will we know when the person is in the terminal stages of the disease?
   - Weeks to months
   - Hours to days
   - Imminent

Questions: Symptoms

3. What symptoms will the person likely have?
   - Can anything be done for the symptom(s)?
   - Talk about your concerns

4. How are the different organ systems working?
   - Gut/GI tract:
   - Kidneys

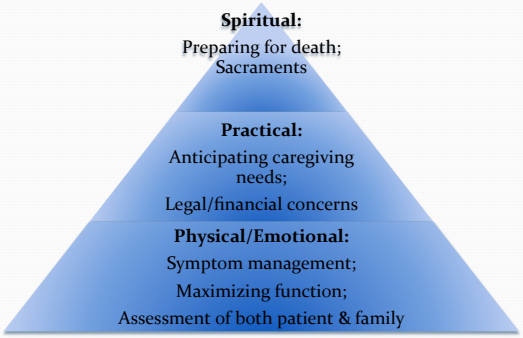
Questions: Resuscitation

5. Would attempts at resuscitation be successful?

6. Ask if there is a palliative care service available

Solutions

- Ask questions
- Gather information
- Ask more questions!
- Incorporate Catholic teachings



Resources

Ethical and Religious Directives for Catholic Health Care Services *Fifth Edition*

Comfort & Consolation: Care of the Sick and Dying: A Pastoral Letter from the Bishops of Maryland
http://www.mdcathcon.org/endoflife

www.getpalliativecare.org