MANAGING SYMPTOMS AT THE END OF LIFE

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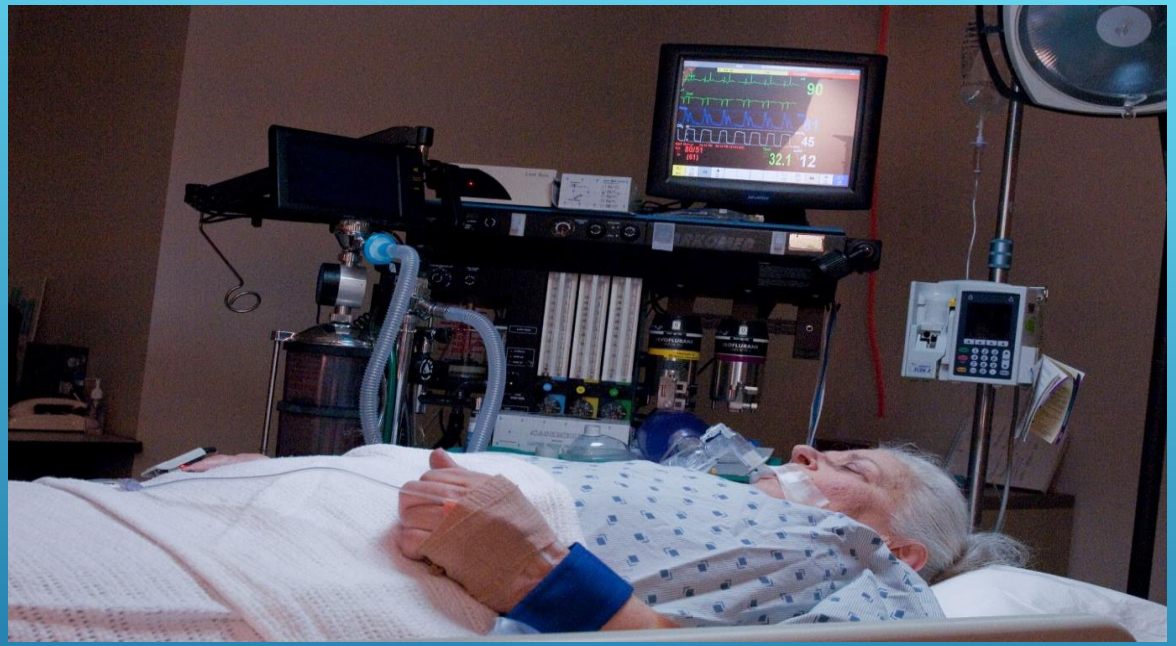
DISCLOSURES

- Dr. Sandra Sanchez-Reilly has nothing to disclose

SESSION OBJECTIVES

- Discuss the common physiologic symptoms, signs and treatment approaches for patients near the end of their lives
- Become skilled at common family concerns on the days preceding death and be aware of the need for psychosocial support and comforting strategies
- Describe how to pronounce a patient death



MRS. FLORES..

IS MRS. FLORES DYING?

- 78 year old woman with a two year history of breast cancer refractory to treatment (chemotherapy and radiation), which has now metastasized to her spine and lungs. Her functional status has been declining significantly over the past couple of months.
- Brought to the ER by daughter
  - Uncontrolled pain
  - Has not been getting out of bed
  - Dyspnea

IS MRS. FLORES DYING?

Physical Exam:

Vitals: BP 70/40 HR 150 RR 30 T96.4

Cachectic, somnolent ,ill- appearing, female

Temporal wasting

Lungs: Coarse breath sounds bilaterally

with dullness R base

CV: Tachycardic regular

Extremities: 3+ edema to the knees

Assessment:

Mrs. Flores is terminally ill with metastatic breast

cancer, not responsive to disease-modifying treatment

PALLIATIVE PERFORMANCE SCALE

Palliative Performance Scale(PPS)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

TERMINOLOGY

- **The terminal phase:** can be considered as the period of inexorable and irreversible decline in functional status prior to death

- **Last Hours:** typically considered to be the last 48 hrs prior to death. It is also known as the actively dying phase

MANAGING THE DYING PROCESS

1. Unpredictability of Death
2. Creating the Setting for the Last Hours of Life
3. Physiological Changes and Symptom Management
4. Caregiver Preparation
5. When death occurs

WHY LAST HOURS ARE IMPORTANT

- 90% people die after a long period of illness with gradual deterioration until an active dying phase at the end
- Last hours of living provide opportunity to:
  - Finish business
  - Create final memories
  - Give final gifts
  - Find spiritual peace
  - Say good-bye

PROGRESSION OF SYMPTOMS/SIGNS IN THE LAST TWO WEEKS OF LIFE

- Two semi-distinct stages over 1-14 days
- Difficult to prognosticate with precision within the last few days
- Time of high stress for family and caregivers
- Second guessing past decisions is common
- Most families are unfamiliar with the dying process—not sure what is "normal"

EARLY STAGE

- Bed bound
- Loss of interest and ability to drink/eat
- Cognitive changes
- Increasing sedation; Lethargy
- Delirium: Hyperactive or Hypoactive

LATE STAGE

- Loss of swallowing reflex
- "Death rattle"
  - Pooled oral sections that are not cleared due to loss of swallowing reflex
- Coma
- Fever
- Altered respiratory pattern
- Skin color changes
- Death

AN OPTIMAL CARE SITE HAS…

- Space for patient/family privacy
- Ready availability of medications and equipment to manage distressing symptoms
- Nursing support when needed
- Round-the-clock patient access for family, friends, caregivers

THE SETTING FOR THE DYING PATIENT

- The optimal place to provide care is determined by:
  - Degree of support available from family/friends
  - Physical support for patient turning, bathing
  - Psychosocial support for patient emotional distress
- Frequency of need for skilled nursing support
  - Community resource availability e.g. residential hospice
- Insurance status

OPTIMAL CARE SITE OPTIONS: QUESTION

The following are end-of-life optimal care site options:

1. Home with hospice support
2. Residential hospice
3. Hospital: Inpatient hospice/palliative care unit OR palliative care support
4. Long-term care facility with hospice support
5. All of the above

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LAST HOURS SYMPTOMS DIFFERENCES BETWEEN CANCER AND NON-CANCER DIAGNOSES

- Cancer
  - Pain 40-100%
  - Dyspnea 22-46%
  - More predictable dying trajectory
- Non-Cancer
  - Pain ~ 42%
  - Dyspnea ~ 62%
  - Less predictable dying trajectory

SYMPTOMS-SIGNS OF APPROACHING DEATH

- Functional decline
  - Loss of mobility: bed bound
- Decreasing oral intake
- Neurological Dysfunction
  - Decreasing cognition
  - Loss of swallowing reflex
- Pain
- Altered respiratory pattern
- Fever
- Skin color changes

MANAGING THE DYING PROCESS: GENERAL TREATMENT CONSIDERATIONS

- Switch essential medications to non-oral route
- Stop unnecessary medications/procedures
- Minimal vital signs monitoring
- Limit notification orders to those necessary
  - Frequent monitors can alarm patient/family
  - Numbers can distract family/staff from patient

MANAGING THE DYING PROCESS

- Evaluate for physical symptoms
  - Pain, dyspnea, urinary retention, agitation, secretions, etc.
- Evaluate for non-physical sources of suffering
  - Emotional : Delirium, depression or anxiety
  - Social: lack of financial or caregiving resources
  - Spiritual/ existential: loss of meaning
- Family
  - Contact, engage, and educate
  - Facilitate relationship with dying patient
  - Console

FUNCTIONAL DECLINE

Function gradually declines in the days to weeks preceding death. Secondary to increased illness burden and diminished functional reserve

- Decreased tolerance for activities of daily living
- Bed bound
  - At risk for bed sores

FUNCTIONAL DECLINE INTERVENTIONS

- Patient activity:
  - Allow patient to sit in chair if desired
  - Allow patient to use bedside commode if safe
  - Passive range of motion q 2hrs

- Patient/Family support:
  - Educate: normalize signs/ symptoms
  - Health aides or caregivers assist with ADLS
  - Durable medical equipment
    - Hospital Bed
    - Bedside commode

DECREASING ORAL INTAKE

- All dying patients lose interest in oral intake in the days preceding death
  - Generalized weakness
  - Advance physiologic decline
    - Dysphagia in neurodegenerative illness
- Ketosis will blunt symptom of hunger
- Bedbound patient will not experience symptoms of postural hypotension
- No association between fluid intake and thirst in final days

WHEN ORAL INTAKE IS REDUCED

Diet

- Liquid Diet
  - Fluids with salt: soup, sport drink help hydrate
  - Fluids with caffeine or free water are dehydrating (coffee, tea, colas)
- Remove dietary restrictions
- Let patient eat food of his choice
  - Family bought food OK if in the hospital
- Allow patient to sit up for meals; assist to eat

WHEN THE PATIENT STOPS TAKING FLUIDS

- Patients with fluid overload are not dehydrated (e.g. ascites or peripheral edema)
- Dehydration in last hours doesn't cause distress
- Parenteral fluids generally not recommended
  - Worsen edema or ascites
  - Increase secretions (GI and respiratory)
  - Patient may need to be restrained if confused
  - If IV fluids are used, suggest a limited time trial

WOULD IV HYDRATION AND MONITORING HELP?

125 abdominal cancer patients who received laboratory examinations in the last week before death.

- IV Hydration:
  - Hydration group (n = 44), who received 1L or more of artificial hydration per day both 1 and 3 weeks before death, vs. non-hydration group (n = 81)
  - The mean albumin level 1 week before death was significantly lower in the hydration group than in the non-hydration group (P = 0.015).
  - There was no significant difference between the groups in the mean blood urea nitrogen/creatinine, sodium, or potassium levels 1 week before death.

- Oral Hydration: 53 patients who had oral fluid intake of less than 500 mL/day throughout the last 3 weeks and completed a fluid balance study,
  - Calculated fluid balances did not significantly differ between the patients with deterioration of dehydration signs, edema, ascites, and pleural effusion during the final 3 weeks and those without.

Active artificial hydration might result in hypoalbuminemia, with no clear beneficial effects on normalizing blood urea nitrogen/creatinine, sodium, or potassium levels.

DECREASED ORAL INTAKE INTERVENTIONS

- Meticulous oral care
  - Good hygiene
  - Moistening of the lips with petroleum Jelly to avoid cracking
  - Mouth cleaning and moisture with artificial saliva or baking soda mixture
- Caregiver Education
  - Do not force feed
  - Provide ice chips and small sips of liquid as tolerated
- Discontinue non-essential medications

NON-ORAL CHOICES FOR MEDICATIONS

Feeding Tube

- If already in place can be useful route for administering medications
  - Change essential medications to liquid
  - Some medications can be crushed

Rectal

- It may be inconvenient if other routes possible
- Available suppositories (e.g. acetaminophen)

or can be compounded

- Caution if rectum is blocked by stool or tumor

NON-ORAL CHOICES FOR MEDICATIONS

Intravenous (IV)

- Starting and maintaining may be difficult
- Not feasible in home setting
- If available provides reliable means of administering medications

Subcutaneous

- Small IV or butterfly needle inserted directly under the skin (abdomen or thigh)
- Allows injection small volumes of medicines
- Avoids burden of finding/maintaining IV access

NON-ORAL CHOICES FOR MEDICATIONS

Transcutaneous

- Mucosas (oral, nasal)
- Specific formulations (e.g. Fentanyl)
- Transcutaneous use of IV or oral formulations

Transdermal

- Specific transdermal formulations
  - Fentanyl
  - Scopolamine

QUESTION

Mrs. Flores is not eating and daughter thinks that you should do something so she doesn't "starve to death". On physical exam she is somnolent and has 3+ pitting edema which of the following are appropriate?

- Start IV fluids 125cc/hr for dehydration
- Provide meticulous oral care
- Educate caregiver about decrease in oral intake as a part of normal dying process
- Give Albumin IV to improve edema and bring fluid back to the vascular space
- Start total parenteral nutrition (TPN)

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TOPICAL MEDICATIONS

- Topical Opioids and Pain:
  - Malignant ulcers (morphine gel compound)
  - Malignant mucositis (morphine mouthwash)
- Topical non-opioids and Pain:
  - Diclofenac Emulgel, ketoprofen gel, piroxicam gel, diclofenac plaster: Localized muscle skeletal pain
  - Topical high-concentration capsaicin (derived from chili peppers): post-herpetic neuralgia or neuropathic pain (50%)
- Topical Agents and Nausea:
  - ABH gel (Ativan/Benadryl/Haldol): It is ineffective for nausea due to erratic absorption

CARDIOPULMONARY RESUSCITATION CONSIDERATIONS

- **Resuscitation is <u>not an effective end-of-life treatment</u>**
  - Terminal process won't allow physiologic circulation
  - 0% CPR survival to discharge in terminally ill patients *
- Enter DNR order
- At home complete out-of-Hospital DNR

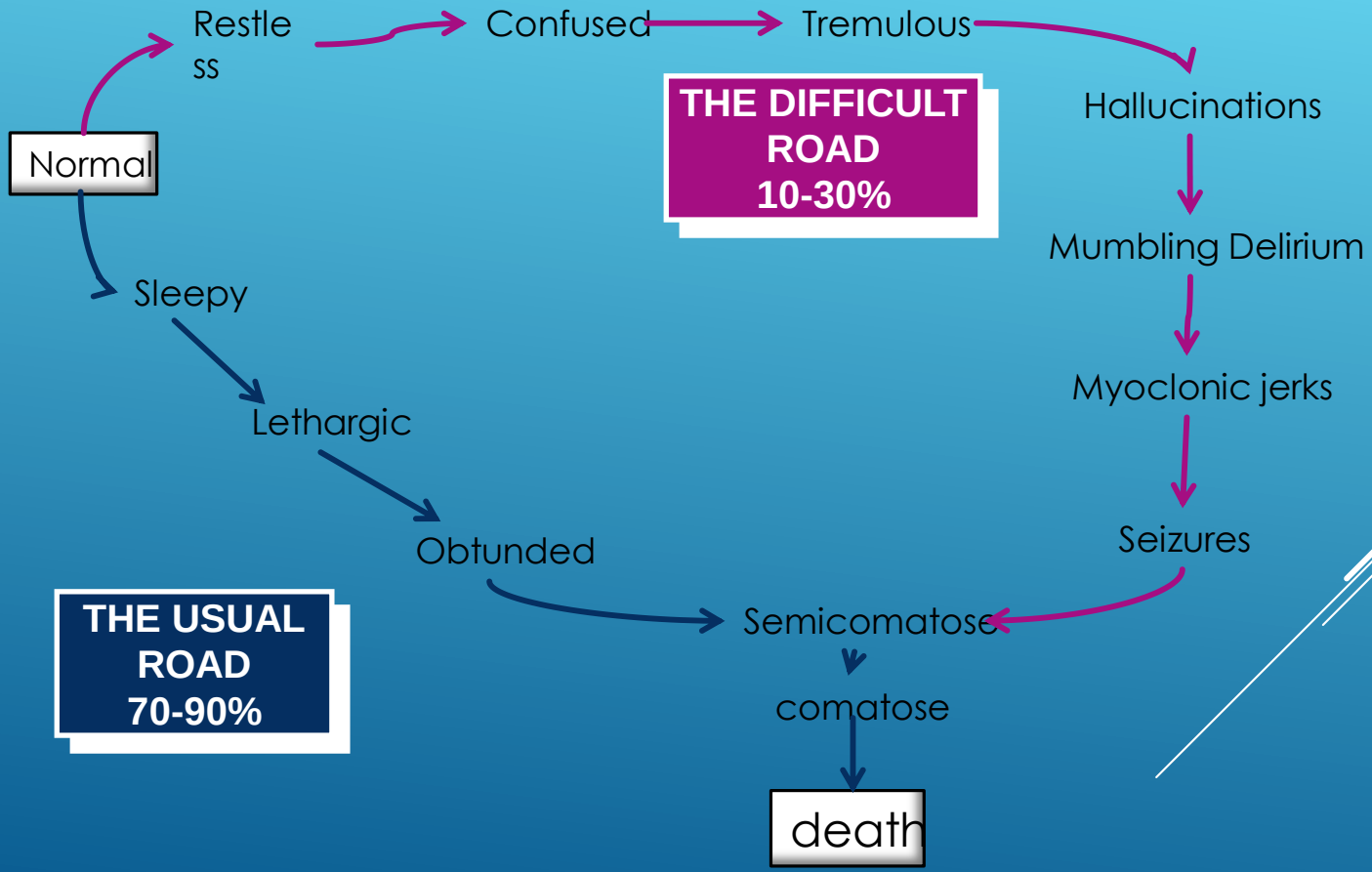
Terminology

- DNR - *Do Not Resuscitate* – Implies that successful resuscitation is possible yet choosing not to do so
- Do Not Attempt Resuscitation (DNAR)
- Allow Natural Death (AND)

NEUROLOGIC DYSFUNCTION

- Decreasing level of consciousness
- Communication with the unconscious patient
- Terminal delirium
- Changes in respiration
- Loss of ability to swallow, sphincter control

NEUROLOGIC DYSFUNCTION: ROADS TO DEATH



USUAL ROAD: DECREASED COGNITION

- Increased drowsiness
- Decreased ability to communicate
- Loss of swallowing ability
- Loss sphincter control
- Death

Caregiver Education

- Awareness > ability to respond
- Assume patient hears everything

DIFFICULT ROAD: TERMINAL DELIRIUM

- Medical management
  - benzodiazepines
    - lorazepam, midazolam
  - neuroleptics
    - Haloperidol, chlorpromazine
- Seizures
- Family needs support, education

QUESTION

Mrs. Flores appears agitated, talking to her dead husband and having bugs crawling on her bed. Which one of the following is a recommended treatment for delirium in the last few days of life:

A. Anti-histaminic agent for sedation

B. Full work-up (laboratories, CxR, etc)

C. Empiric antibiotics

D. Short-acting benzodiazepine

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SKIN /WOUND CARE

Last hours focus is on comfort not healing

- Skin
  - Routine bathing to maintain hygiene
  - Moisturize skin
  - Protect fragile skin
- Wound care
  - Minimize frequency of dressing changes
  - Control infections with topical antibacterial/ antifungal
  - Absorb odors
  - Masking odors: alternative smells

"DEATH RATTLE"

Terminal syndrome characterized by retained oropharyngeal secretions caused by:

- Inability to swallow
- Lack of cough
- Multi-system shut-down

Which leads to loud noisy breathing

- Often very distressing to families
- Not always associated with dyspnea

“DEATH RATTLE” TREATMENT

- Keep back of throat dry by turning head to side
  - Discontinue artificial hydration/feedings
  - Avoid deep suctioning
  - Mouth Care
  - Anticholinergic drugs to dry secretions?

TYPES OF ANTICHOLINERGIC MEDICATIONS

- Scopolamine patch topical behind ear q3 days
- Atropine eye drops 2-3 in mouth q4 hours or until effective
- Glycopyrrolate 1 mg orally or 0.2 mg subcutaneously or intravenously every four to eight hours as needed

Do Anticholinergic medications really work?

- Terminally ill adult hospice inpatients who developed death rattle were randomized to double-blind treatment with atropine or placebo. Study drug was given as a single sublingual dose.
- Noise from breathing was monitored at baseline and at two and four hours.
- Sublingual atropine given as a single dose was not more effective than placebo in reducing the noise associated with death rattle.

QUESTION

After few hours, Mrs. Flores has been progressively more sleepy; she has now starting making a loud gurgling sound that has her daughter extremely concerned.

The death rattle can best be managed by which

of the following:

- **A.** Anti-cholinergic medication
- **B.** Deep suctioning
- **C.** Mechanical Ventilation
- **D.** Increasing fluids to loosen secretions

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PAIN MANAGEMENT IN FINAL DAYS: PATIENT WITH SIGNIFICANT PAIN

- Assume that pain will continue to be present until death
- Do not discontinue opioids as mental status declines
- Stop sustained-release medicines and use immediate-release medications at this point
- ↓ Opioid dose for opioid toxicity e.g. myoclonus
- Diminished renal/hepatic function may need less opioid
- Judge analgesic need on physical signs
  - Grimacing and groaning; Tachycardia
- Use a trial of increased analgesics for suspected pain
- Use non-pharmacologic analgesics (e.g. music/massage)

PAIN

Caregiver education

- Normalize signs/symptoms
- Affirm the importance of family observations for potential pain
- Confirm the role of analgesics near end-of-life
  - Clarify confusion about opioid double-effect
  - Encourage non-pharmacological treatments

ALTERED RESPIRATORY PATTERN

- Respiratory patterns in final days:
  - Increased or decreased rate or depth
  - Cheyne-Stokes breathing
  - Periods of apnea: death is likely within 24-48 hours
- Rapid breathing is often distressing for families/ caregivers
- Treatment is only indicated for rapid breathing (30 resp/min)
- Careful titration of opioids can help control respiratory rate to a range of 10-20 breaths/min
- Use oxygen only if it appears to reduce distressing symptoms

FEVER

- Fever is common 1-3 days prior to death
  - Aspiration pneumonia is likely etiology
- Most cases:
  - Scheduled acetaminophen (rectal if not taking PO) OR NOT TREAT IF PATIENT COMFORTABLE
- Refractory cases:
  - Cooling blankets
  - Parenteral NSAIDs or steroids

SKIN COLOR CHANGES

A variety of changes may occur in the final hours to days before death:

- Vasoconstriction with cyanosis
- Mottling
- Ashen color
- Digital necrosis
- There is no specific treatment approach

ASSISTING FAMILY

- Advise family about alerting other loved ones as to gravity of patient's status
- Facilitate family presence
  - Order permission for family to visit or stay
  - Arrange visits for military and incarcerated relatives
- Enlist Pastoral Care and Social Work if appropriate

COACHING FAMILIES ABOUT LAST HOURS CHANGING NEEDS

Sense /desire	Family loss	Coaching
Hunger	Nurturing	Other ways to nurture
Thirst	Nurturing	Mouth moist
Speech	Communication	Can still hear…
Vision	Being seen	May be conscious
Hearing	Being heard	Can still feel…
Touch	Physical presence	Transition to 'non-physical' relationship

SIGNS OF IMPENDING DEATH

Sign	Median time patient death
Respiratory Secretions (Death rattle)	23h (82h SD)
Respirations with mandibular movement	2.5h (18h SD)
Cyanosis/mottling	1.0h (11h SD)
Lack of radial pulse	1.0h (4.2h SD)

SIGNS OF DEATH

- Heartbeat/respirations Absent
- Pupils fixed
- Skin color appears yellow/waxen
- Body temperature drops
- Muscles relaxed
  - Jaw falls open
  - Eyes remain open
  - Sphincters relax
  - Body fluids may trickle

DEATH PRONOUNCEMENT

- Death
  - not a difficult diagnosis no need for “pupil exam, assessment for pain”
  - Confirm death has occurred by absence of respirations and heartbeat
- Comfort family
- Complete necessary paperwork
  - Death note
  - Death certificate
- Communicate with medical examiner for selected cases

DEATH PRONOUNCEMENT SKILLS

- *Anticipate* impending death and prepare family
- If called, inquire about circumstances
  - family present/not, anticipated/not
- If family present, assess 'where they are'
  - Already grieving or need ritual to believe person died
- 'Sacred silence'
- Console
- Next steps
- Self-care

Hallenbeck, JAMA May 2005

TELEPHONE NOTIFICATION OF DEATH

- Avoid if possible
- Identify where recipient of news is (home, freeway etc.)
- Identify yourself and relation to the deceased
- Give brief 'advance alert':
  - I'm Sorry I have some sad news
- Slow recipient *DOWN,*
  - NOT – "you must come right in away"
- Identify contact person at hospital
  - "Ask for Dr. … or Nurse …
- Empathetic statement

QUESTION

Mrs. Flores has been receiving comfort care in a private room. You are called by nursing to pronounce Mrs. Flores' death. Which of the following would be appropriate actions to take when pronouncing someone's death (Select all that apply)

- ❑ Ask the family members to step out of the room
- ❑ Note absence of heartbeat
- ❑ Note absence of respiration
- ❑ Note absence of pain reflex by deep sternal rub or nipple pinching

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SUMMARY

"Life is pleasant. Death is peaceful. It's the transition that's troublesome"

Isaac Asimov

- Death is a sacred moment in the life-cycle
- Families will remember a person's death and how healthcare providers helped or not
- Healthcare providers can relieve the patients' suffering and ensure a comfortable death
- The healthcare team can coach patients and families through their last hours of living

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APPENDICES – SELF STUDY MATERIALS

- Choose Wisely: http://aahpm.org/uploads/education/publications/Spring_13_Quarterly_Feature.pdf

- If comfortable, include email address.

CLOSING SLIDE