THE CARE OF THE ACTIVELY DYING PATIENT

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No disclosures

PLEASE ANSWER THE FOLLOWING QUESTIONS

1. Why did you become a doctor? (ONE SENTENCE)

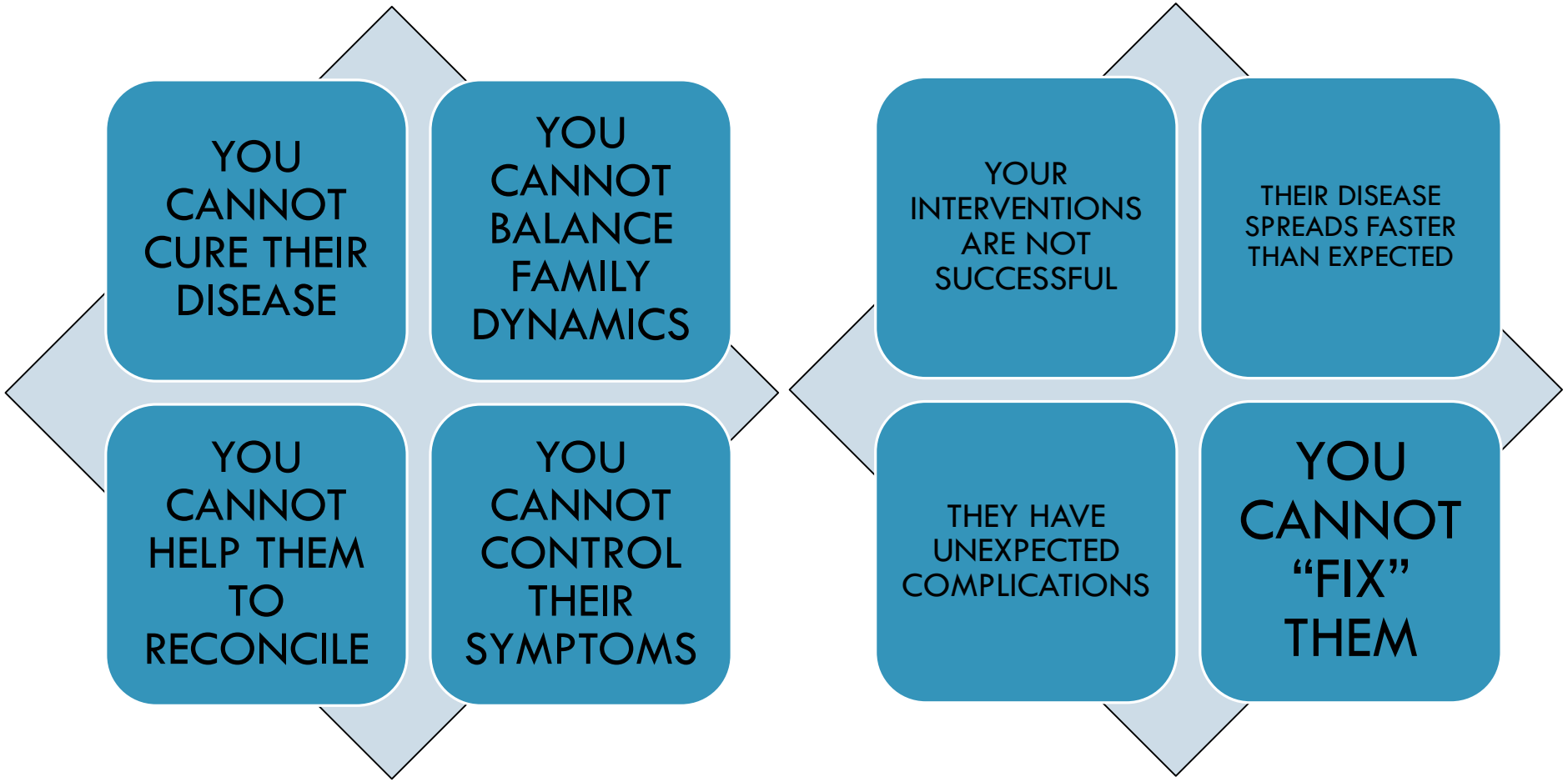
2. How confident are you being the responsible physician caring for an actively dying patient? (0-10, 0: I am totally flustered and lost caring for dying patients, 10: I am a board certified hospice physician and that is my true calling)

3. What fears, worries, concerns, anxieties do you have surrounding the care of a dying patient?

WHY DID YOU BECOME A DOCTOR?

What if you cannot?

WHAT DOES IT MEAN WHEN



YOUR PATIENT IS DYING

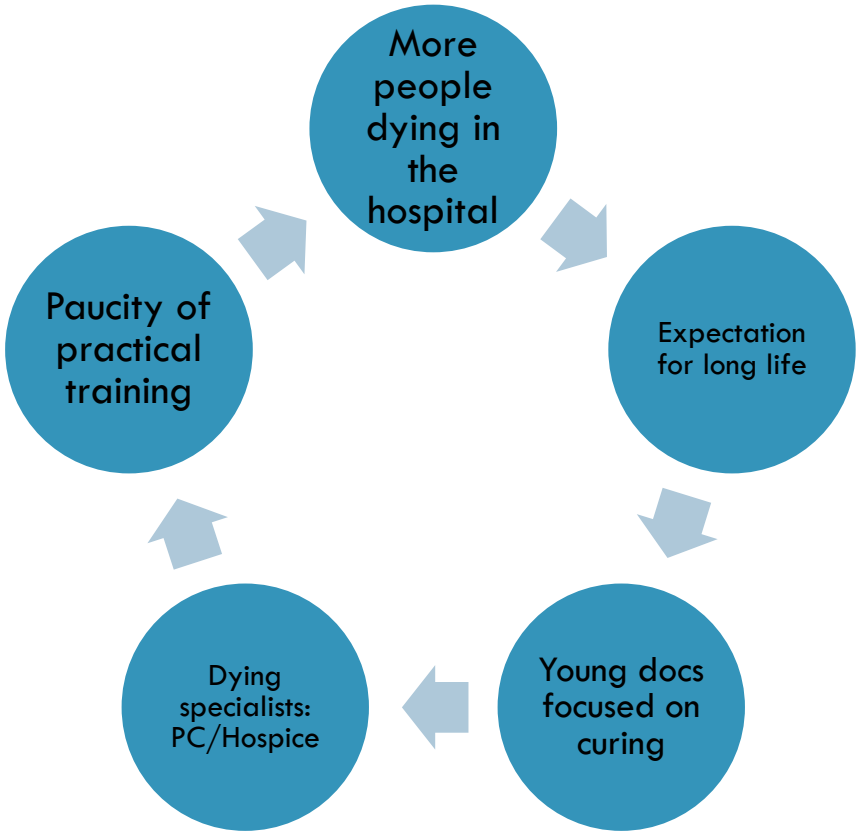
Help
- Support
- Ease suffering

Heal
- Empower
- Educate

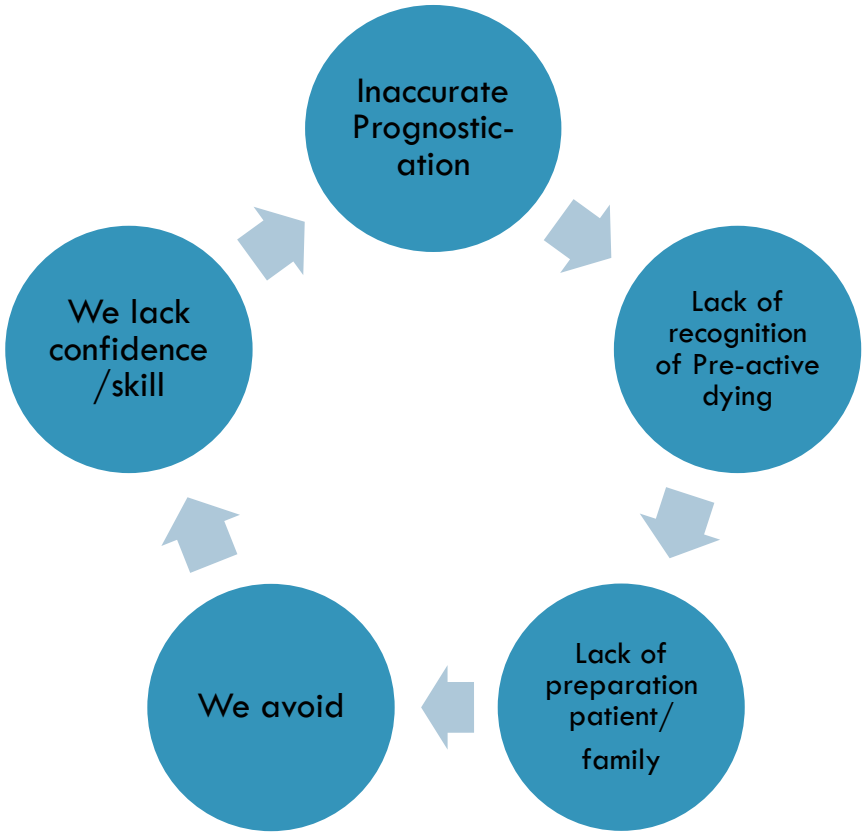
Cure
- Acceptance
- Preparation

2018

Medical Culture



Risks



AGENDA

- Stages of Dying
- Prognostication
- Defining Team
- Symptoms
  - Dyspnea
  - Agitation
  - Secretions
  - Pain
- Disease Specific
  - ESLD
  - Respiratory
  - Renal
  - Substance Abuse
- Cultural Considerations
- Protocols/Order Sets
- Hot Topics
  - Palliative Sedation
  - Physician Assisted Suicide

STAGES OF DYING

Clinical Death

- No heartbeat
  - No circulation; toxin flush, stoppage of oxygen delivery > end organ strain
- No spontaneous respirations
  - No renewal of oxygen reserves
- Process is still reversible > recoverable with intervention > CPR, intubation + ventilation

Biological Death

- **4 to 6 minutes** after Clinical Death
- Cellular death, brain cells first to die
- Process is not reversible > Resuscitation is impossible

Prior to Clinical Death?

- Harder to define
- Stages more variable, host specific

STAGES OF DYING

STAGES OF DYING, PRE-ACTIVE

ANOREXIA

- Refusal of food/fluid
- Volitional +/- care plan +/- dysphagia
- Feeding via TF/PEG or giving IV fluids can change the rate of dying

WITHDRAWAL/ FATIGUE

- Reduced energy stores
- Less spontaneous movement

REDUCED URINE OUTPUT

- Peripheral edema
- Pleural effusions

TERMINAL DELIRIUM

- Hyperactive
- Endorphin release, hepatic encephalopathy, uremia, hypoxia
- Hallucinations, agitation

STAGES OF DYING, ACTIVE

CHANGE IN BREATHING PATTERN

- Cheyne-Stokes
- Death Rattle
  Agonal

TERMINAL DELIRIUM

- Hypoactive
- Obtundation, Coma

PERIPHERAL VASOCONSTRICTION

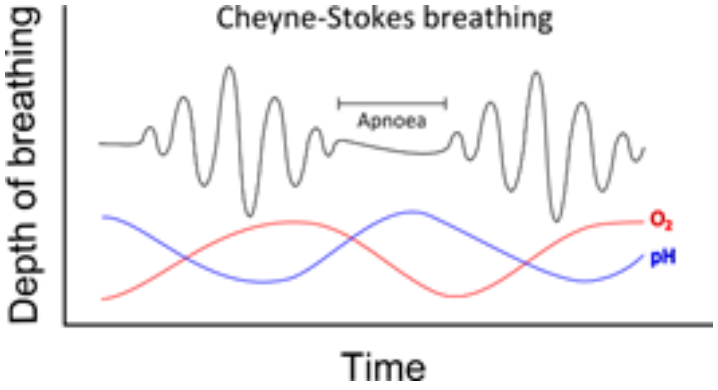
- Cool extremities
- Diminished capillary refill
- Mottling

HEMODYNAMIC CHANGES

- Hypotension
- Tachydysrhythmia > Bradycardia

Cheyne-Stokes

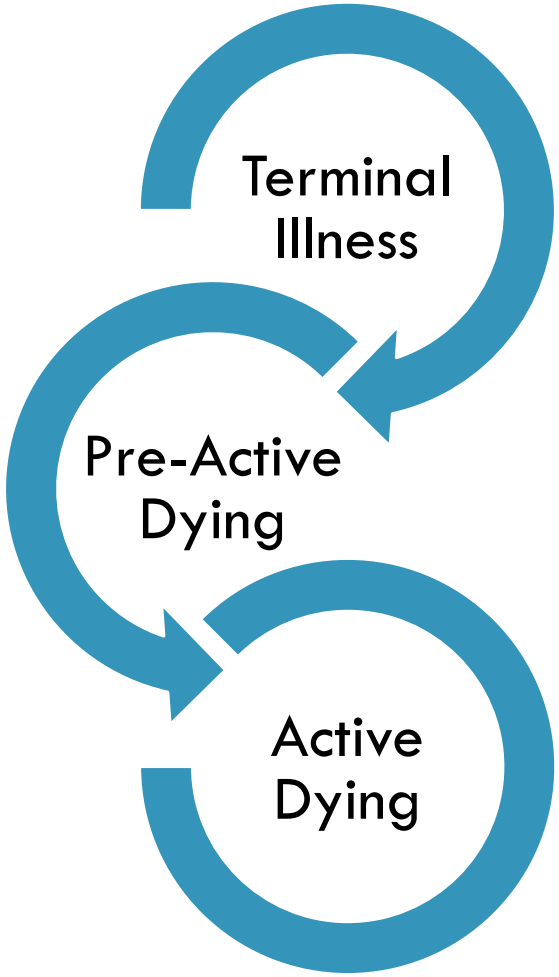
Abnormal pattern of breathing characterized by progressively deeper and often faster breathing followed by gradual decrease resulting in temporary cessation – apnea. Oscillation of ventilation: Apnea/Hyperpnea with Crescendo/Diminuendo pattern. Changing serum partial pressures of oxygen and carbon dioxide.



Agonal

Abnormal pattern of breathing and brainstem reflex characterized by gasping, labored breathing, often accompanied by strange vocalizations and myoclonus. Possible causes include cerebral ischemia, extreme hypoxia, anoxia.

PROGNOSTICATION



Where is your patient in this process?

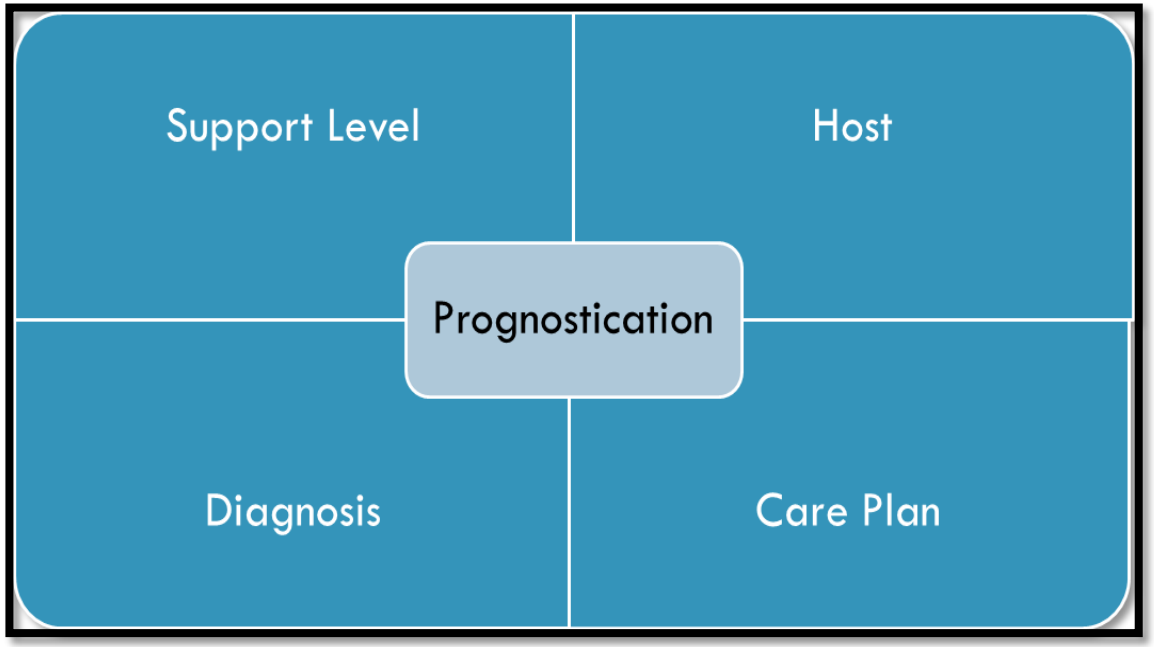
-Guide your team
-Guide the family/surrogate
-Guide your interventions

PROGNOSTICATION

-Influenced by Level of Support
- Life Support
  - Intubated, Pressor Support, CRRT
- Natural Death

-Influenced by Etiology/Diagnoses
- Young person with head injury, intact brainstem
- ESLD + AAH with progressive coagulopathy
- Elderly person with VT with defibs, deactivate defibrillator

-Influenced by Host



-Influenced by Dying Care Plan
- Keep Intubated, full ventilator and pressor support but DNR
  - "Continue current level of support with no escalation of support", no CPR
- Extubate to comfort care
  - Discontinue ventilator, vasopressors, antibiotic, antidysrhythmic support, liberalize medications focused on comfort

PROGNOSTICATION

To plan you have to prognosticate

- Where will the patient die?
- Do I have time to get him/her home with a hospice team?
- Do I have time to move to a private room, out of the ER or ICU?
- Administrative pressure to move the patient from the hospital?

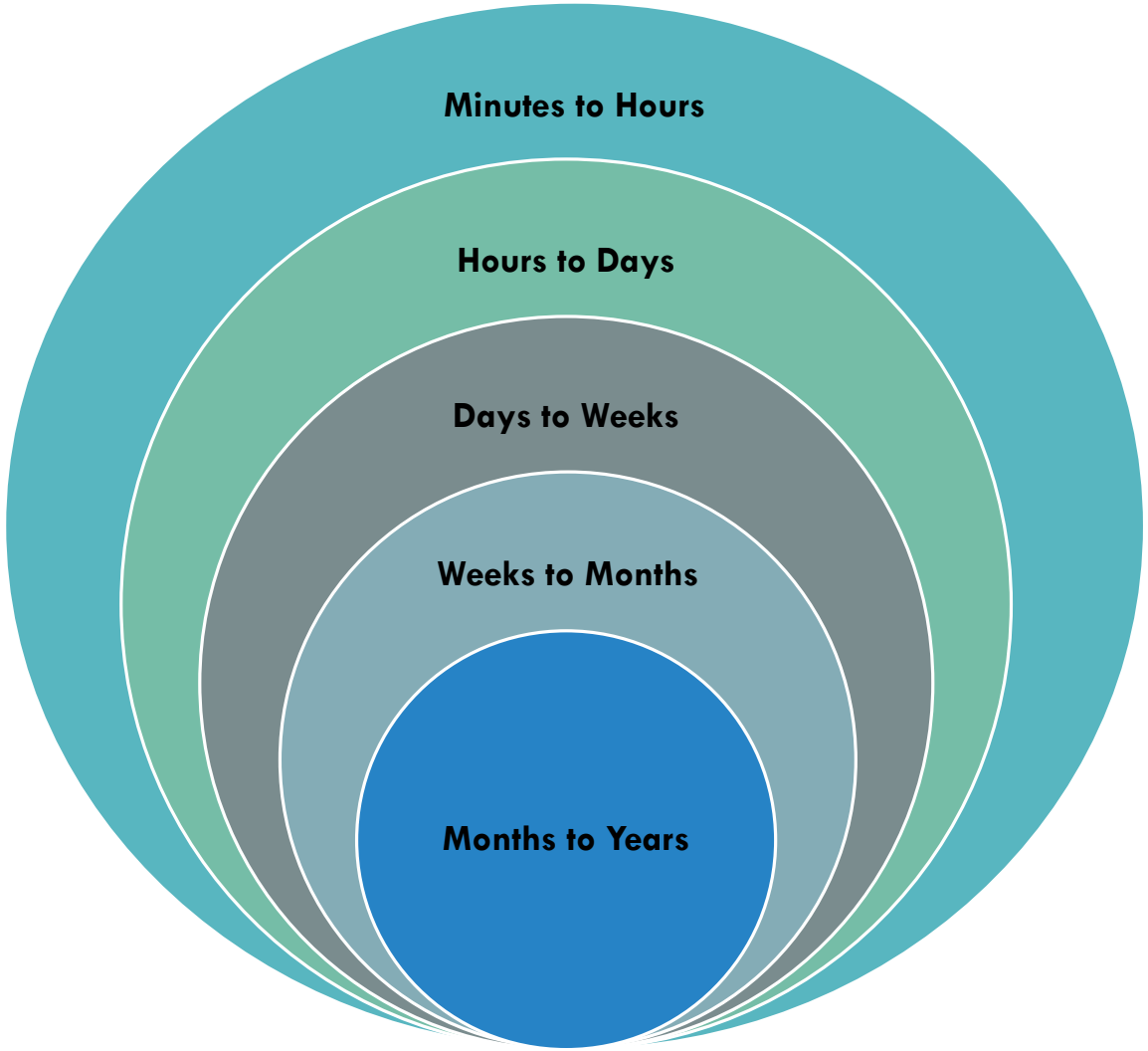
To prognosticate you have to communicate

- Communicate with specialists/hospice, palliative care docs
- Communicate with your team
- Communicate with the family/surrogate

ALWAYS give a range

- If we are wrong, which we will be, we lose **trust**, lose **therapeutic working relationship**

PROGNOSTICATION



PROGNOSTICATION: RANGES

Minutes to Hours

- Hemodynamically unstable, immunocompromised with severe sepsis
- High level of ventilator and pressor support, withdrawal to comfort care

Hours to Days

- Severe head trauma but intact brainstem, comfort care
- Young patient with single organ failure, i.e. ESLD + AAH

Days to Weeks

- End Stage COPD
- End Stage Heat Failure

Weeks to Months

- Metastatic Lung Cancer with malignant effusion
- Cholangiocarcinoma with peritoneal carcinomatosis and malignant ascites

Months to Years

- Many Stage 3-4 oncologic diagnosis
- Moderate dementia with first hospitalization for aspiration, new dysphagia

DEFINING TEAM

RN

- Plan for medications
- Do not assume comfort/experience w/ dying process – if necessary request SW support
- Withholding of medication for fear of causing respiratory depression
- Misunderstanding about DNR vs. comfort care

Respiratory Therapist

- Facilitate extubation, present for symptom management, family preparedness
- Misunderstanding about expected breathing pattern changes during active dying
- Plan for supplemental O2, NIPPV vs. NC vs. none

PT/OT/SLP

- Delegate update to RN
- Change to comfort feeding pre-active or NPO if actively dying
- PT order to move, surrogate has decided against

All Specialists actively on record

- Family interactions, consistent message
- Cancellation of further studies – imaging, labs, endoscopy, EEG, etc.

Surrogate decision maker

- Invitation to be present, permission to not be present

SYMPTOMS

Avoid Overpathologizing

- "She is crying so we better start medication for depression."

Avoid Overnormalizing

- "He is dying, of course he is anxious!"

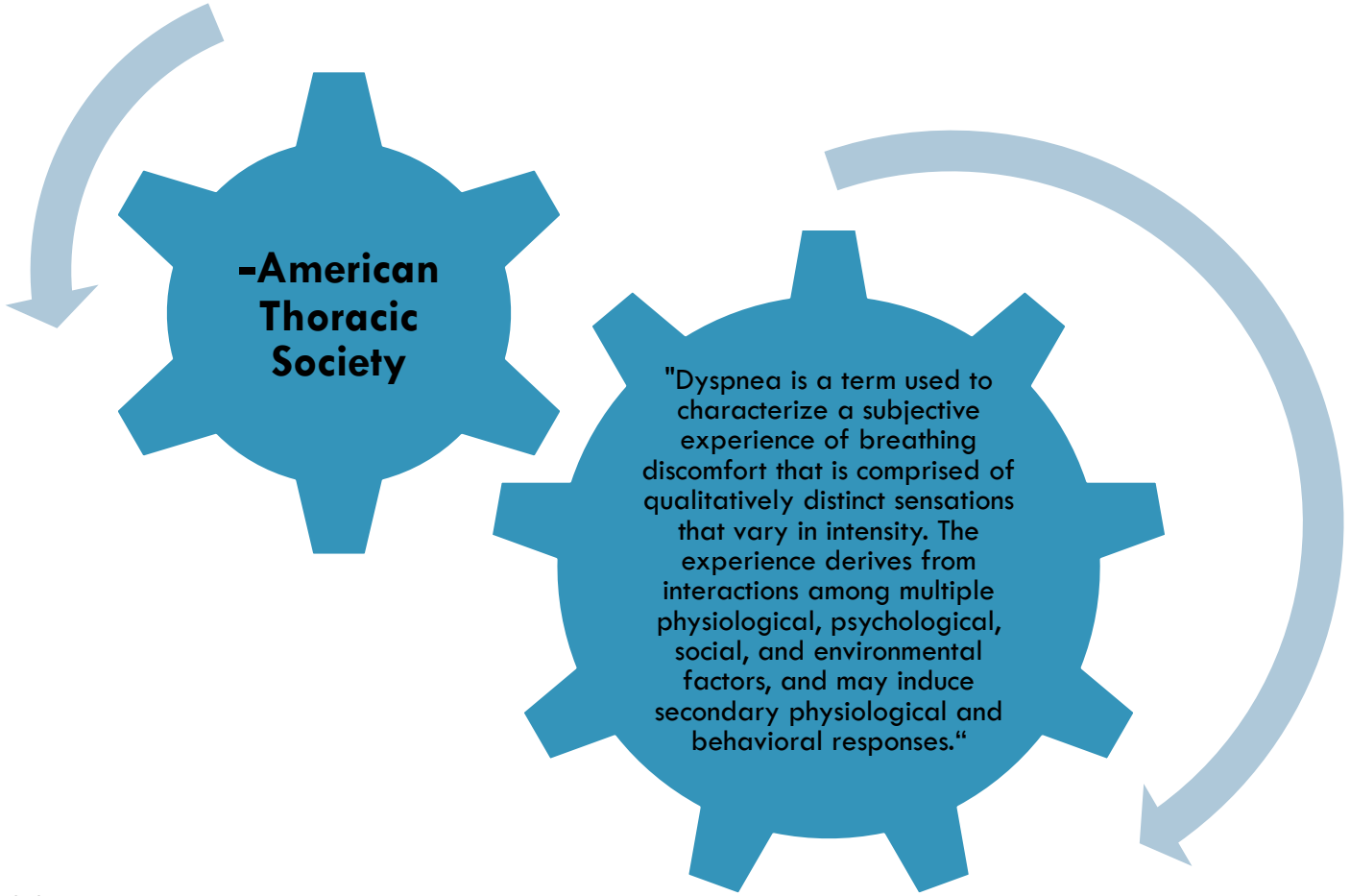
Prepare family

- Expectations during the dying process
- Intention to relieve symptoms, not to hasten death

SYMPTOMS

Dyspnea

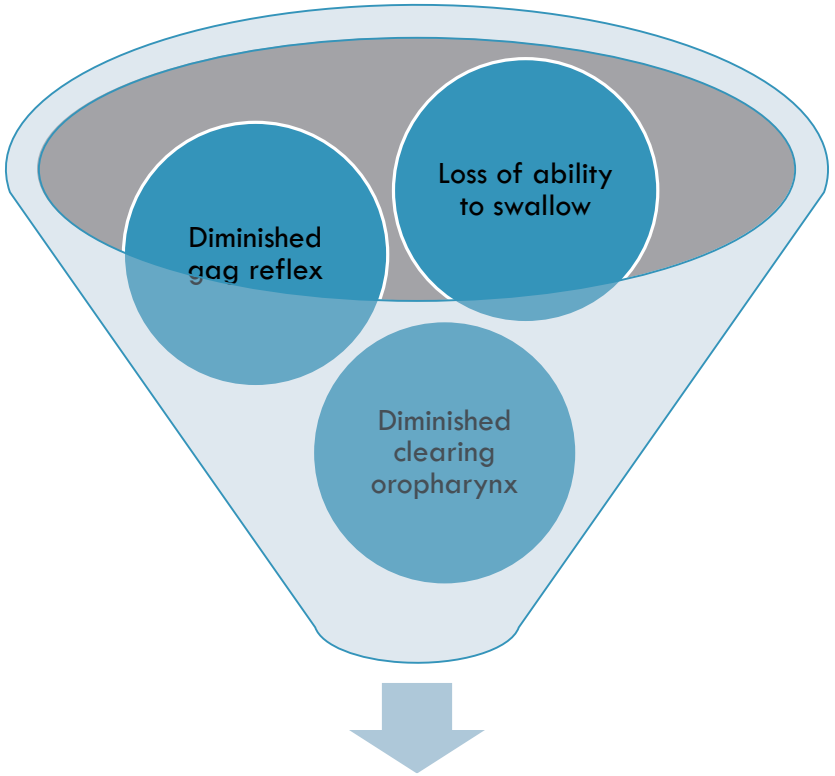
- Nonverbal dyspnea indicators
  - Grimace, gasp, wide eyed, tachypnea
- Scheduled low dose opioid liq/tablet
  - Morphine 2.5 or 5mg liq conc SL TID
- Concentrated opioid prn
  - Titrate to goal relaxed facial muscles and RR < 20
- If anxious concentrated benzodiazepine
  - Lorazepam , liq conc SL 2mg/mL prn
- Fan towards face
- Reposition to upright
- Reduce need for exertion, cancel PT/OT
- NC or simple mask
- Discontinue IV hydration and TF
- If pre-active consider palliative thoracentesis or pleurex catheter placement



SYMPTOMS

Secretions

- Glycopyrrolate
  - 1-2 mg orally, bid to tid
    - Oral absorption can be unpredictable
  - 0.2-0.4mg iv or sq q 4 to 8 hrs
    - Very effective but takes hours to work, not for imminent death
- Hycosamine
  - 0.125 mg oral dist tabs, 1-2 tabs PO
  - 0.125 mg/mL oral soln , 1-2mL q 4 hrs prn
  - *both glycopyrrolate and hycosamine less likely to exacerbate delirium because neither cross the BBB.
- Atropine
  - 1% ophthalmic ggt , 1-2 drops q 1-3 hrs prn.
  - Works fast
  - Cheap, most hospice formularies
  - Crosses BBB, can exacerbate confusion/delirium
- Scopolamine patch
  - 1-3 patches transdermal q 3 days
  - 0.4 mg sq 4-6 hrs prn
- Discontinue IV hydration and TF
  - Active dying phase IV hydration will not improve renal perfusion or urine output. Excess fluids > anasarca, pulm and peripheral edema.

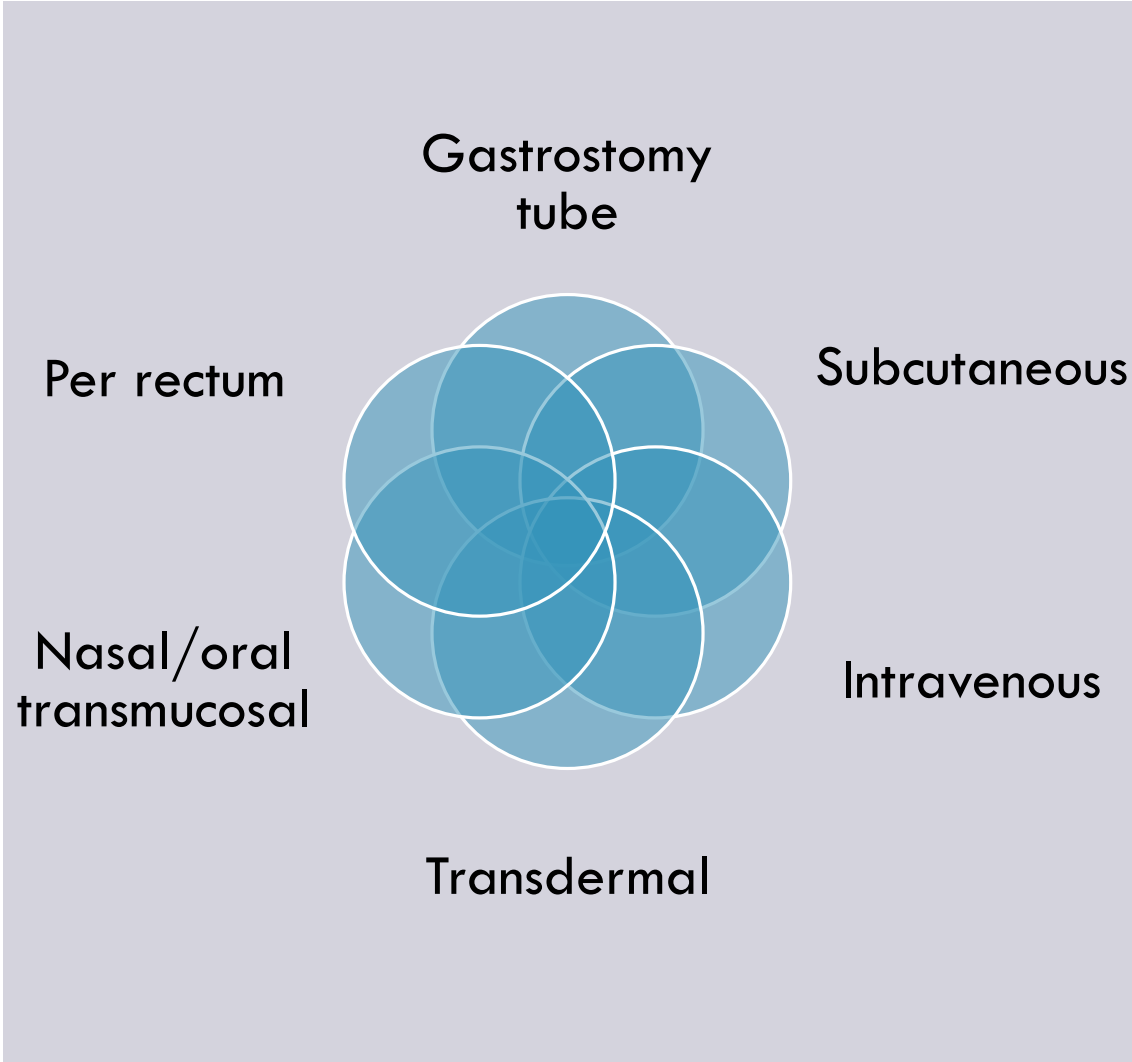


Accumulation tracheobronchial secretions

SYMPTOMS

Pain

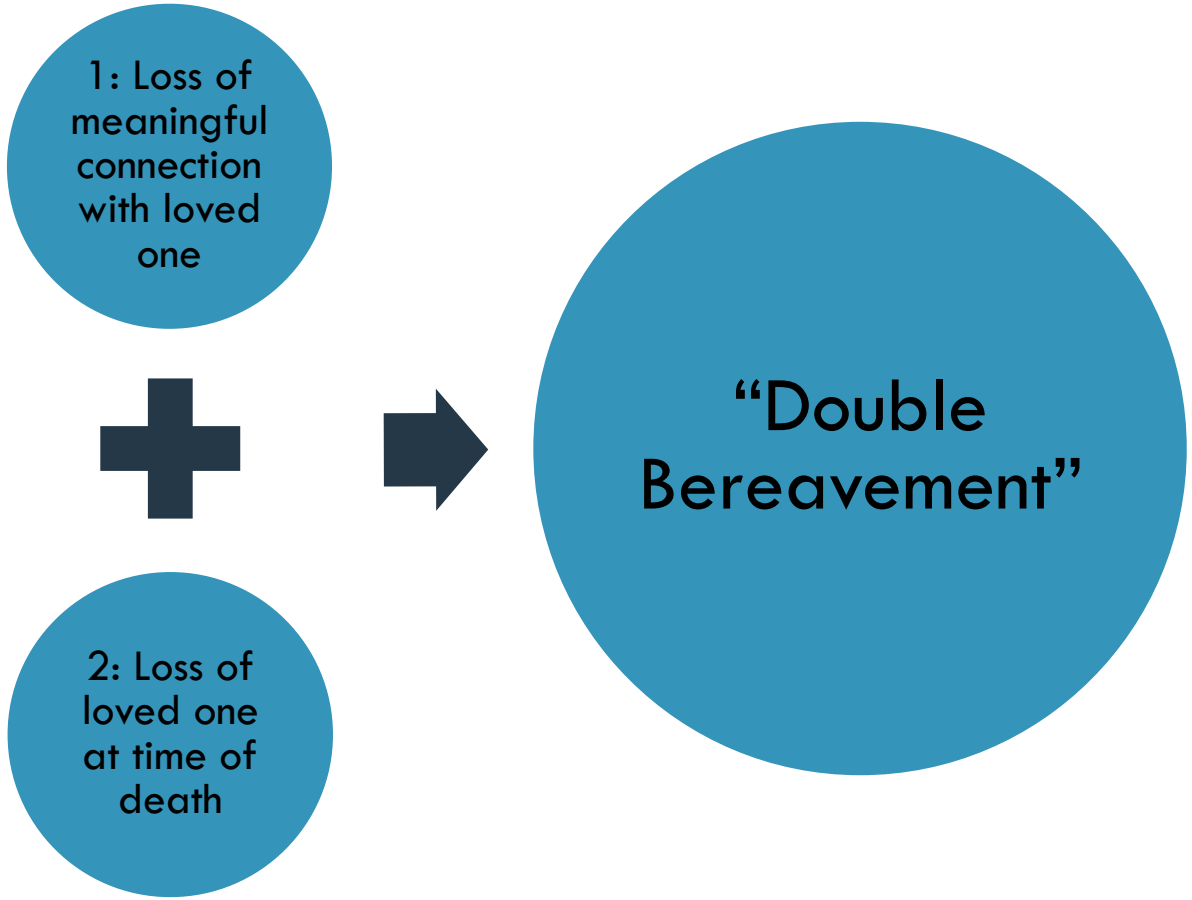
- Concentrated opioid
  - Morphine, liq conc SL 20mg/mL – active neuro metabolites
  - Oxycodone, liq conc SL 5mg/5mL
  - Fentanyl – liver failure, can use transdermal patch
  - Hydromorphone – very effective for pain + dyspnea, potent
- Methadone
  - NMDA receptor antagonist
  - Neuropathic + Somatic coverage: PR, PO, IV
- Non-opioid adjuncts
  - Ketorolac , IV
  - Acetaminophen PR
  - Corticosteroids : Dexa 1-4mg PO, SC, IV
  - Topical Anesthetics: Lidocaine 5% patches
  - Neuropathic Pain Agents, if can take PO
    - TCA, SSRI and SNRI
    - Anticonvulsants: Gabapentin, Lyrica
- Refractory pain at end of life
  - Consider Interventions
    - Nerve blocks, spinal epidural
    - Anesthesia/Interventional pain/OB - pudendal blocks/GI - celiac plexus blocks



SYMPTOMS

Anxiety/Agitation

- Antipsychotics – first line
  - Risperdal
    - 0.25 -0.5 dissolve tab q 12 hr
  - Olanzapine
    - 2.5-5mg po q d
  - Quetiapine
    - 12.5-25mg po q 12hr
  - Haldol
    - 1mg po or 0.5mg IV q 1 hr to effect, then 6-12 hr
    - 5mg SC q 6 hrs
- Benzodiazepine – second line
  - Lorazepam 0.5-1mg po/sl/iv/sc/pr hourly until effect
- Evaluate medications
  - toxic or paradoxical effect, withdrawal syndrome
    - Rotate opioids, discontinue anticholinergics
- Consider constipation/urinary retention
- Undertreated pain
- Reduce stimulation
  - Television, window, open door, family



SYMPTOMS

Loss of Sphincter Control

Incontinence of urine and stool

Distressing to patients/family

Discuss catheter w/surrogate
- Minimize changing/cleaning/reduce caregiver demand
- Form of restraint?

Anticholinergic meds for symptoms
- Urinary retention > discomfort

Profuse intractable diarrhea
- Consider rectal tube

Inability to Close Eyes

Cachexia > loss retroorbital fat pad

Orbit falls posteriorly within socket

Eyelids do not fully oppose

Ocular lubricants
- Hydroxypropyl methylcellulose opth soln
- Ointment
- Physiologic saline
- Education

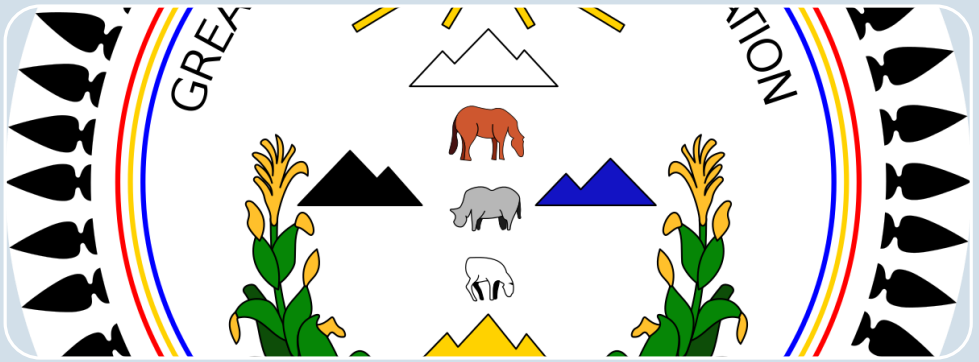
DISEASE SPECIFIC CONSIDERATIONS

ESLD	COPD	RENAL	SUBSTANCE ABUSE
Encephalopathy	Dyspnea/Tachypnea	Uremia	Withdrawal
Coagulopathy	Tolerance relative hypoxia	Dialysis questions	Tolerance
Severe 3rd Spacing	Family fear suffocation	Fluid overload/anasarca	Decreased seizure threshold
Asterixis	Terminal wheeze/rattle	Asterixis	Complicated family dynamics

DISEASE SPECIFIC CONSIDERATIONS

HEART FAILURE	CANCER	DEMENTIA	CONGENITAL
Dyspnea at rest	Cachexia	Unrealistic Expectations	Comfort with "abnormal"
Edema/anasarca	Long history of "fighting"	Anorexia/dysphagia	"Quality of life"
Gurgle/death rattle	Opioid tolerance	Caregiver distress/fatigue	Staff distress
Disorientation, Na++	Oncology dependence	Cultural influences	Inability to communicate

CULTURAL CONSIDERATIONS



Hopi:

- Burial before sunset the day of death, ceremony before sunrise
- Frequent questions about when patient will die
- Matrilineal society

Navajo:

- Family not present at time of death
- Staff distress over family leaving
- Body intact to enter afterlife

PROTOCOLS

Familiarize yourself with Order Sets

- Withdrawal of ventilator order set
- Comfort care order set

Post Mortem Protocols

- Does the body go to the morgue, or directly to the mortuary?
- Who calls the mortuary?
- Who signs the death certificate?
- Medical Examiner Case protocol
- Organ Donor Network involvement

HOT TOPICS

- Palliative Sedation
  - Use of progressively higher levels of sedation to help relieve otherwise intractable and distressing physical symptoms at the very end of a patient's life
  - Purpose to relieve otherwise uncontrollable suffering, not to intentionally end a patient's life or to hasten death
  - Aim is the lowest level of sedation that relieves symptoms
  - Critical to have experts in Palliative Care and Ethics involved
  - Critical to have surrogate decision maker, MPOA involved for informed consent

HOT TOPICS

- Physician Assisted Death
  - A physician provides the means for a patient to voluntarily end his or her life
  - Patient decides when and if the medication is actually used, and the patient is responsible for and must be capable of taking the medication him or herself
  - Usually a potentially lethal prescription for barbiturates
  - Illegal in the United States except for Oregon, Washington, Montana and Vermont
  - Often persistent requests for death represent poor symptom management, lack of psychological and spiritual support on the part of the patient, fear of suffering on the part of a family member

"Better is possible. It does not take genius. It takes diligence. It takes moral clarity. It takes ingenuity. And above all, it takes a willingness to try"

A. Gawande

THANK YOU

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