Penn Medicine
Lancaster General Health Physicians

Palliative Medicine

Optimize the Time Living in the Actively Dying

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Objectives:

- Identify an actively dying patient
- Discuss related symptoms and treatment of those symptoms
- Recognize family needs and concerns during this time and beyond

Case 1: Harry

- 88 yo male with recently diagnosed appendiceal cancer, yet to see oncology. You admitted him yesterday for uncontrolled nausea and vomiting.
- Imaging showed peritoneal carcinomatosis, partial small bowel obstruction and widely metastatic disease.
- You spoke with patient and his family on admission and they elected to focus on comfort measures only as Harry feels his quality of life even in the short time since diagnosis has severely declined and he knows time is short.
- You placed an NG tube to suction for comfort, consulted hospice, and started IV decadron.
- You follow up this morning to check on patient's symptoms before his hospice meeting which is scheduled at 1 pm.

Case 1 continued:

- On arrival you notice a significant change in Harry
- His mental status is altered. He is awake but has a non-focused gaze. He is breathing erratically and occasionally yelling out in pain that he can't localize.
- The PTCA notes that his blood pressure is very low and sometimes he doesn't breathe for 20 seconds at a time.

- What signs and symptoms are you detecting that are indicative that the patient is actively dying?

Definition

- Includes diagnosis of progressive irreversible disease with a limited prognosis
- No consensus definition
- Also called “Imminent Death” or “terminally ill”
- Time period: 24 hours to about 14 days
  - No consensus
- Not a step wise fashion
  - Mottling
- Prognostication is difficult
  - Those who enter having good nutritional status likely to have longer prognosis to those who are cachectic
  - Ex: Sudden Aneurysm and brain death vs Metastatic stomach cancer

Hui, David, et al. “Concepts and Definitions for “Actively Dying

Stages:

- Early
  - Bedbound
  - Lost of interest or ability to take PO
  - Sleeping more/Altered Mentation
- Middle
  - Further loss of consciousness with only minimal periods of the day alert and awake if any
  - Decreasing urine output
- Late
  - Pooled oral secretions “Death Rattle”
  - Obtundation
  - Irregular breathing
  - Neck hyperextension
  - Mottling

Signs

- Reviewing life events or memories
- Seeing previously passed loved ones
- “Staring to the heavens”
- Withdrawal/Mood changes
- Telling you they think they’re dying

Signs continued…

- Physical Signs
  - Positive Likelihood ratio of death within 3 days
    - Non-reactive pupils
    - Decreased response to verbal or visual stimuli
    - Drooping of nasolabial fold
    - Hyperextension of the neck
  - Death less than 3 days
    - Death rattle
    - Respiration with Mandibular movement
    - Cheyne stokes breathing
  - 3-7 days
    - Mottling
    - Terminal Delirium
    - Terminal lucidity
  - 7-28 days
    - Intractable pain

Hui D., Dos Santos R, et al

Considerations

- Goals of Care
  - Live as long as possible (comes with some suffering!), Quality of life, Functionality
  - Manage Expectations
  - “I wouldn’t be doing my duty as your provider if I didn’t tell you what I’m worried about”
- Timing
  - Sudden or Long time coming?
- Location
  - Is the patient dying in a hospice home vs home and how should medications be used for ease of dosing accordingly?
- Pharmacologic Intervention
  - Is the patient having active symptoms that can be treated vs family concerns and worries
    - Shared decision making on treating symptoms anyway

Case 2: Martha

- 75 year old with coronary artery disease and heart failure admitted to hospice for end stage heart failure
- After 3 months of home hospice she was transferred to your skilled nursing facility as family could no longer take care of her at home
- Over the last month she has decompensated and overnight she was deemed to be actively dying.
- You are beginning your shift at 9 am Monday and the nurse calls you and says the family is asking “is there anything we can do to make her more comfortable?”

- What symptoms do you expect to be treating when you arrive in Martha’s room?

Summary of Common Symptoms:

- Pain
- Dyspnea
- Secretions
- Anxiety
- Agitation

Initial General treatment options for the actively dying

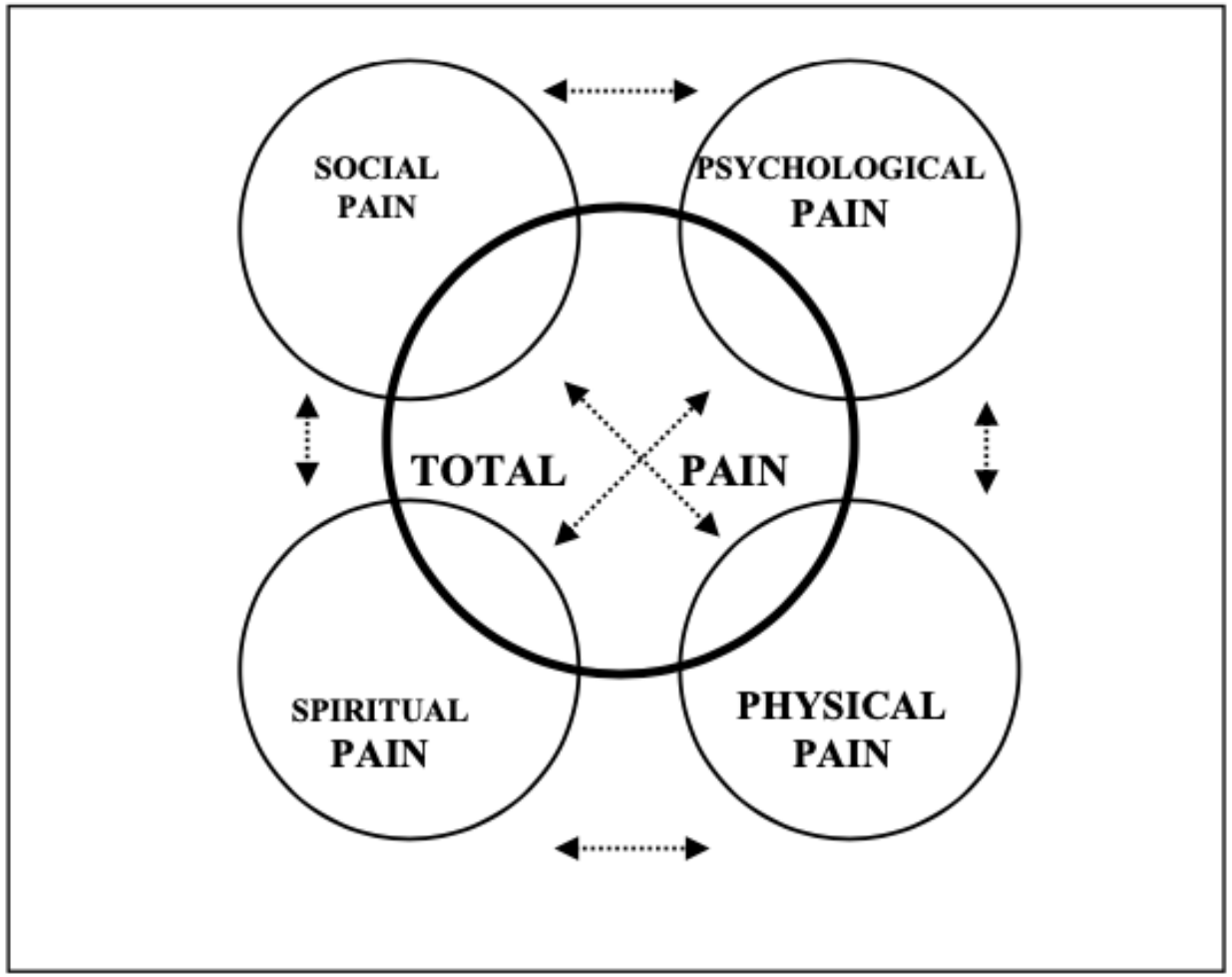
- Clear Communication in your documentation and to family
  - Its okay to say “the patient is actively dying and this is why”
- Discontinue anything that is not contributing to comfort
  - Lab draws
  - Medications
  - Vitals
  - IV hydration
- Equipment
  - Hospital bed, commode, suction, pads
- Excellent mouth and body care
  - Involve family if they want to be involved!
- Address total pain/suffering (more below)

Pain

- Evaluation of source
  - Due to underlying illness: metastatic cancer, hip fracture, neuropathic pain (neuropathy)
  - Terminal pain- stiffness from immobility
- Treatment: comfort care measures
- Pharmacologic:
  - Opioids
    - Consider Opioid naïve
    - PO oral morphine (5-10 mg q3-4 hours) vs IV/SQ morphine (2-4 mg q1-2 hours) vs continuous opioid infusion if symptoms unable to be controlled
  - Steroids (also lack of energy or anhedonia?)- Decadron 2-4 mg (can be IV, SubQ, IM, or oral), usually minimal cost
  - Neuropathic Pain
  - Intermittent vs frequently recurring or chronic and worsening
- Route
  - Able to take PO? Pain so uncontrolled they can't wait for PO to get to steady state? Do the need a continuous infusion?

Whitecar, P. S., et al. (2000a, February 1). *Managing pain in the dying patient*. American Family Physician

Total Pain:



Total pain. Palliative Care Network of Wisconsin. (2023, November 30).

Dyspnea

- Subjective feeling of shortness of breath
- Could be due to underlying lung involvement of disease or complications regarding the disease (anemia, weakness)
- Anxiety !
- What do you know already? What workup can you do without being too invasive? (evaluation and examination are essential)
- Clarify goals and intentions of workup
- Treatment:
  - O2 for comfort, Fan, Comforting environment, DC IV fluids that could be contributing
  - Opioids
    - PO oral morphine (5-10 mg q3-4 hours) vs IV/SQ morphine (2-4 mg q1-2 hours) vs continuous opioid infusion if symptoms unable to be controlled
  - Benzodiazapines, Antitussives, Bronchodilators, Diuretics, Steroids

Excessive Secretions

- Due to waning consciousness, lose ability to clear secretions from airway
- No evidence that patient's find this disturbing
- Can be very disturbing to family
- Prognosis: one study found 76% patients with terminal illness died within 48 hours of onset
- Treatment
  - Non-pharmacologic: DC IV fluid, positioning of patient (lateral recumbent), gentle (never deep) suctioning, family counseling
  - Pharmacologic: Next slide

Wilders H, Menten J. Death rattle: prevalence, prevention and treatment. *J Pain Symptom Manage*. 2002; 23:310-317

Excessive oral secretions: Pharmacologic treatment

- Scopalamine Patch: 1.5 mg q72 hours
- Atropine SQ/IV: 0.1 mg q4 hours PRN
- Atropine PO: 1% SL Drop 1 drop q4 hours PRN
- Glycopyrrolate IV/SQ: 0.2-0.4 mg q4 hours PRN
- Glycopyrrolate PO: 0.5-1 TID PRN

- Consideration
  - Blood Brain Barrier
  - Prognosis
  - Expense

Anxiety/Agitation

- Assess sources
  - uncontrolled pain, full bladder, constipation
  - Unresolved conflict in family, existential suffering
- Setting
  - Calm environment, lighting, noise
- Discontinue anything that could be contributing
  - adjust steroids
  - activating antidepressants
- Benzodiazepines
  - Lorazepam 1-2 mg IV/SQ/Oral Solution q2-4 hours PRN (can also use for at risk of seizures)
- Antipsychotics
  - Haloperidol 1-2 mg IV/SQ q2-4 hours PRN (can also use for nausea)

Terminal Delirium

- 1-2 weeks before death approximately
- Acute change in mentation and attention
- Hyperactive or Hypoactive
- Fluctuating levels of consciousness
- Workup and treatment of the underlying cause may no longer practical and may cause more suffering
  - Dependent on goals of care

Terminal Delirium Continued

- Treat symptoms
  - Non-pharmacologic: control sensory stimulation, involve (or don't*) family accordingly, frequent reorientation as appropriate
  - Pharmacologic: No consensus, depends on hyper vs hypoactive
    - No significant different found between symptom relief in first or second generation antipsychotics
    - Lorazepam with Haldol vs Haldol alone might be more beneficial for agitation
    - Hyperactive patients who are at risk to themselves or others should be treated pharmacologically
- Delusions or Hallucinations: Use an Antipsychotic
  - Haloperidol 1-2 mg IV/SQ q2-4 hours PRN
- Underlying anxiety surrounding delirium: Benzodiazepines
  - Lorazepam 1-2 mg IV/SQ q2-4 hours PRN
- Treat if family worries they are suffering

Case 3: Benny

- 66 yo male with recent diagnosis of rapidly progressing dementia admitted to the inpatient hospice unit due to actively dying and uncontrolled symptoms.
- The last RN assessment is that the patient is comfortable, having agonal breathing, and “death rattle.”
- You are rounding on your patient in the next room and a family member calls you to the hallway, crying, stating “Benny is choking to death, isn’t there something we can do?”
- When you approach the room multiple family members are surrounding the patients bed crying.

- After your own assessment of the patient, how would you address the family’s anticipatory grief?

Treating the Family of the Actively Dying

- Common Family concerns and how we address them:
  - How do we know if they are in pain/suffering if they can't tell us?
  - "We're Starving them!"
  - Should we stay here (at bedside)?
  - Can they hear me?
  - What do we do after they die?
- You don't have to have all the answers!

Discussions with Families

- Empathetic listening and Exploration
  - Avoid overly reassuring or “explaining away”
  - Name the emotion
- Provide information and education
  - Ask for permission
- Nutrition
  - Dying patients do not need nutrition like we do
  - Good oral care, sponge swabs is best supportive care
  - Be attuned to cultural/religious concerns and address them by shared decision making
  - Artificial Nutrition and Hydration
    - May worsen suffering!
- After the death
  - Be informed of basic next steps to inform family, autopsy
- Grief and Bereavement Resources
  - Hospice!

Interdisciplinary Team: Life Line

- Hospice Nurses
  - Excellent at signs and symptoms of actively dying
- Social Workers
  - Family and patient anticipatory anxiety and bereavement support
- Chaplains
  - Existential distress
- Volunteers/Aids
  - Address many needs that clinical team members can't or don't have time for
  - Personal Care needs
- Use other clinicians
  - Run symptoms by them, talk it out. The art of medicine

Practice!!!

- Case 1:
  - 88 year old with COPD on hospice and actively dying at home within the last 24 hours. Family is worried that the patient is choking because of pooled secretions in airway. What is the next first step the nurse should take:
    - A. Call the doctor to come to the patient's house to workup the "choking"
    - B. Call 911
    - C. Administer atropine 1% 1 drop sublingual and educate family on extent of patient suffering
    - D. Tell the family not to worry

Practice !!!

- Case 2:
  - 92 year old with terminal dementia recently admitted to the inpatient unit due to uncontrolled dyspnea. You are called to the bedside because the nurse noticed acute uncontrolled agitation. When you arrive at bedside the patients 4 children are arguing around their mother about how to best keep her calm. The patient is restless but not a threat to herself or others. What is the next best step?
    - A. Ask the nurse to administer lorazepam 4 mg sq and Haldol 5 mg sq now
    - B. Ask the nurse to continue to care for the patient as she is doing and step out with the family to provide education on how to best keep a calm environment in the room for the patient and expectations regarding agitation and anxiety at the end of life
    - C. Talk louder than the family to see if the patient can hear you

Questions?

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