Symptom Management in the Last Days of Life

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Acknowledgement

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Disclaimer

While this program provides educational information, this information is not medical advice. Health care providers should exercise their own independent clinical judgment. Some of the information cites the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling.

Accordingly, the official prescribing information should be consulted before any such product is used.

Objectives

- Describe 5 common physiologic signs, symptoms and their treatment options in approaching death.
- List common family concerns in the day's before death and counseling strategies.

Case Question

You have been involved in the care of a 74 yo woman who is dying. The family has decided to take the patient home with Hospice to care for her until she dies. This will be the family's first experience with a home death. They ask you:

- What will death look like?
- How will I know when to call Hospice for help?
- What can I do for her now?

How do you answer the family's questions?

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

An optimal care site has…

- Space for patient/family privacy
- Easy access to medications and equipment used for management of distressing symptoms
- Nursing support when needed
- Open-door policy at all times of day so that family/ friends/caregivers can visit the patient

Site Options

- Home with hospice support
- Residential hospice
- Hospital: Inpatient hospice/palliative care unit
- Long-term care facility with hospice support

Although Hospice does not have to be involved in the care of every dying patient, it is ideal - especially if the patient wants to die at home. See Hospice module for detailed information on hospice resources and eligibility

Stages of Dying

- There is a progression of signs and symptoms in the last 2 weeks of life
- Two semi-distinct stages over 1-14 days
  - Early Stage
  - Late Stage
- Difficult to prognosticate with precision within the last two weeks
- 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

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

Late Stage

- Loss of swallowing reflex
  - Can lead to pooled oral secretions and noisy breathing, aka the “Death Rattle”
- Coma
- Fever
- Altered respiratory pattern
- Skin color changes
- Death

Symptom Management

- *The following slides provide summary information.*
- *More detailed information on symptoms of pain, delirium, dyspnea and use of artificial hydration/nutrition can be found in other modules.*

Loss of Mobility

- Mobility gradually declines in the days to weeks preceding death.
  - Check for bedsores
    - Frequent turning (q1-2h)
    - Protect sites of bony prominence
    - Special mattress/bed to reduce bedsore risk

Loss of Mobility

- Caregiver Education
  - Normalize signs/symptoms
  - Caregivers may try to get patients out of bed if not told that being bedbound is expected
  - Review bedsore prevention strategies

Loss of Cognition

- Gradual decline in cognitive ability
  - Increasing sedation and/or
  - Delirium: hypoactive or hyperactive, followed by
  - Obtundation and Coma

- Delirium management
  - Psychotropic medications PRN (e.g. Haloperidol)
  - Calm environment
  - Frequent reminders of place/people

Loss of Cognition

- Caregiver Education
  - Normalize signs/symptoms
    - especially in hyperactive delirium
  - Encourage a calm environment, with familiar objects and favorite music
  - Assume the patient can still hear and feel
    - Encourage family members to say their goodbyes and offer statements of love

Decreasing Oral Intake

- Most dying patients lose interest in oral intake in the days preceding death
  - Ketosis will blunt symptoms of hunger
  - Bedbound patient will not experience symptoms of postural hypotension
  - No association between fluid intake and thirst in final days
  - Oral cavity needs frequent assessment to ensure good hygiene

Decreasing Oral Intake

- Caregiver Education
  - Normalize signs/symptoms
  - Do not force feed
  - Provide ice chips and small sips of liquid as tolerated
  - Mouth swabbing q1hour with baking soda mixture
  - Frequent moistening of lips with petroleum jelly to avoid cracking

Loss of Swallowing

- The “Death Rattle” ensues when a patient is unable to swallow
  - Retained oropharyngeal secretions lead to …
  - Loud noisy breathing—often very distressing to families
  - Treatment
    - Discontinue artificial hydration/feedings
    - Anticholinergic drugs to dry secretions
      - Atropine, scopolamine, glycopyrrolate, others
    - Repositioning of patient
    - Oropharyngeal suctioning – use only if necessary

Pain

- The patient with a history of significant pain entering the final days:
  - Assume that pain will continue to be present until death
  - Do not discontinue opioids as mental status declines
    - Dose reduction may be needed due to diminished renal/hepatic function: myoclonus is a sign of opioid toxicity
  - Use physical signs of potential pain to judge analgesic need:
    - e.g. grimacing and groaning, tachycardia, tachypnea
- Treatment
  - Use a trial of increased analgesics for suspected pain
  - Use non-pharmacologic analgesics

Pain

- The patient without significant pain entering the final days
  - New, severe pain due to the dying process is unlikely, although discomfort from lack of mobility can occur
  - Use a trial of analgesics if pain is suspected

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

- In the final days, the respiratory pattern usually changes to one or more of the following:
  - Increased or decreased rate or depth
  - Cheyne-Stokes breathing
  - Periods of apnea
- Treatment is only indicated for rapid breathing, which is often quite distressing for families/caregivers
  - Careful titration of opioids can help control respiratory rate to a range of 10-20 bpm
- Use oxygen only if it appears to reduce distressing symptoms

Altered Respiratory Pattern

- Caregiver Education
  - Normalize symptoms/signs
  - Review role of oxygen
  - Review significance of apneic periods: death is likely within 24-48 hours

Fever

- Fever is common in the 1-3 days prior to death
  - Pneumonia due to aspiration is the most likely cause
- Scheduled rectal acetaminophen will control most fevers
  - cooling blankets, parenteral NSAIDs or steroids can be used for refractory cases

Fever

- Caregiver Education
  - Normalize signs/symptom
  - Review management options

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

Skin Color Changes

- Caregiver Education
  - Normalize signs/symptoms

Signs of Death

- Prepare family members of signs when a patient is dying at home
  - Absence of heartbeat and respirations
  - Pupils fixed
  - Skin color appears yellow/waxen
  - Muscles relaxed-jaw falls open
  - Eyes remain open
  - Loss of bowel and bladder control

Death Pronouncement

- Requirements vary by hospital/state
- Clinician role
  - Confirm death has occurred by absence of respirations and heartbeat
  - Comfort family
  - Complete necessary paperwork
  - Communicate with medical examiner if necessary based on suspected cause of death-check local laws on what cases must be reported.

Case Question

You have been involved in the care of a 74 yo woman who is dying. The family has decided to take the patient home with Hospice to care for her until she dies. This will be the family's first experience with a home death. They ask you:

- What will death look like?
- How will I know when to call Hospice for help?
- What can I do for her now?

How do you answer the family's questions?

Answer

- *What will death look like?*
  - Explain common signs/symptoms
- *How will I know when to call Hospice for help?*
  - Families should be aware that they can call Hospice anytime there is a change in the patient's condition or if the family is worried that the patient is suffering in any way. Reviewing what is expected at the time surrounding death may also help alleviate common anxieties.
- *What can I do for her now?*
  - Highlight care that family can provide such as…
    - Repositioning
    - Monitoring for signs of discomfort
    - Oral care
    - Massage and gentle touch
    - Creating a familiar environment
    - Saying good-bye

Fast Facts

Supplementary *Fast Facts*:

#001 Diagnosis and Treatment of Terminal Delirium
#003 Syndrome of Imminent Death
#027 Dyspnea at End of Life
#053 Sublingual Morphine
#054 Opioid Infusions in the Imminently Dying Patient
#060 Pharmacologic Management of Delirium; Update on Newer Agents
#109 Death Rattle and Oral Secretions
#149 Teaching the Family What to Expect When the Patient is Dying

https://www.capc.org/fast-facts/

Learning Points

List 3 new things you learned from this presentation.

1.
2.
3.

References

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