

# Symptom Management at the End of Life



Ian Anderson Continuing Education Program  
in End-of-Life Care



# Symptoms at the End of Life

- Current literature emphasizes that too many people still die in pain
- Equally or even more distressing are:
  - Fatigue (asthenia)
  - Anorexia (loss of appetite)/cachexia (loss of weight)
  - Drowsiness or insomnia
  - Confusion
  - Anxiety
  - Dyspnea
  - Nausea and vomiting
  - Constipation & diarrhea



# Effects on Quality of Life

- Physical suffering
- Inability to enjoy remaining life:
  - Simple tasks become a challenge
  - Isolated from loved ones
  - Unable to fulfill remaining life goals
  - Worst fears about dying become realized
  - Destruction of hope for any quality of life



# Quality of End-of-Life Care

## The Patients' View:

### FIVE Components of Quality End-of-Life Care

- 1) Adequate pain **and symptom** management
- 2) Avoiding inappropriate prolongation of dying
- 3) Achieving a sense of control
- 4) Relieving burden
- 5) Strengthening relationships with loved ones

Singer P.A., Martin D.K., Kelner M., Quality End-of-Life Care: Patient's Perspectives, *JAMA* 1999 281(2) 163-168



# Objectives

- Describe the management of common symptoms at the EOL
- Develop a preventive approach to managing patient and family expectations and needs
- Identify clinical problems whose management/diagnosis may merit further exploration



# Three General Rules

1. Any given symptom is as distressing to an individual person as that person claims it to be
2. All treatments, their risks, benefits, & alternatives need to be discussed in context of the dying person's values, culture, goals & fears
3. When illness is advanced & death very near, the exact causes of any given condition are irrelevant and investigations pointless



# Perception of Symptoms at EOL

- Perception of symptoms are worsened by anxiety, fatigue, emotional and psychological stress
- Presence of a psychological component does NOT mean distress should be ignored
- Exploring and alleviating contributing sources of stress will help:
  1. Control symptoms
  2. Lead to better decision-making and
  3. Improve quality of life



# Patient & Family Education

Education on likely course of illness, symptoms & possible complications :

1. Decreases natural fear & anxiety of the “unknown”
2. Develops a plan to alleviate/control symptoms
3. Facilitates decision-making & helps plan for future
4. Helps patients and families to know when to seek prompt medical attention
5. Dispels myth that dying = unavoidable suffering





# Approach to Symptom Management

- Multidisciplinary team approach
- “Around the Clock” medication for continuous symptoms
- Breakthrough medication
- Diary
- Frequent re-assessments
- Palliative Care consult if uncertain, not responding or difficult to control



# Asthenia

- Most distressing symptom in dying patients
- Easy tiring, generalized weakness, or mental tiredness
- May be seen as sign of “failure” or “giving up” by dying person and loved ones
- Difficult to assess. Some tools available:
  1. Edmonton Functional Assessment Tool (EFAT)
  2. Fatigue self-report scale
  3. Fatigue symptom checklist



# Etiology of Asthenia

Likely multifactorial:

- Direct tumor effects on energy
- Paraneoplastic syndromes
- Humoral and hormonal influences
- Anemia
- Chronic infections
- Sleep disturbances
- Fluid & electrolyte disturbances
- Drugs
- Over-exertion



# Non-Pharmacological Management of Asthenia

Develop a plan with patient and families to allow them to perform enjoyed activities:

- Coordinate activities with times of most energy
- Arrange for help from family, home care, CCAC, hospice, nursing home
- Use energy conservation strategies
- Change medications and/or times
- Daytime rest and effective sleep at night
- Physical/occupational therapy consult



# Pharmacological Management of Asthenia

- Among the most difficult symptoms to treat
- Steroids: mechanism not clear –? Euphoria  
dexamethasone 2-20 mg/day  
benefit may decrease after 4-6 weeks
- Metamphetamines: act as psychostimulant  
Methylphenidate 2.5-5 mg qAM, q noon  
Typical dose 10-30 mg qAM & q Noon  
SE: tremulousness, anorexia, tachycardia,  
insomnia & myocardial ischemia



# Anorexia/Cachexia

- Very common in advanced illness
- Frequently associated with asthenia
- May be seen as sign of “failure” or “giving up”
- Increased nutrition often does NOT alleviate cachexia
- Increased nutrition will not halt disease progression



# Anorexia/Cachexia

- Etiologies not well understood:
  1. Hormonal mediators
  2. Humoral mediators: IL-1, IL-6, TNF, leukemia inhibitory factor, D factor
  3. Host-tumor factors
  4. Alterations in metabolism
  5. Greater energy expenditure than supply



# Anorexia/Cachexia-- Treatment

- Search for and treat specific causes:
  1. Nausea/vomiting
  2. Anxiety
  3. Pain
  4. Constipation/diarrhea
  
- If no specific cause found, treat if:
  1. Quality of life = enjoyment of food
  2. To give sense of normalcy in daily living





# Non-Pharmacological Interventions

- Educate:
  1. Common part of dying process
  2. Natural endorphins prevent hunger
- Encourage trials of favorite foods
- Avoid gastric irritants: e.g. spicy foods. milk
- Small frequent meals
- Avoid disagreeable or nauseating smells
- Nutritional supplements



# Pharmacological Interventions

- **Steroids:** mechanism not clear—? Euphoria/ PG inhibition  
dexamethasone 2-20 mg/day  
benefit may decrease after 4-6 weeks
- **Progesterone Drugs:** mechanism not clear – inhibits production of cachexin/TNF  
? appetite stimulant  
SE: nausea/edema/hypercalcemia  
cushingnoid/decreased survival  
megestrol acetate: 200 mg q6-8h  
range 480-1600 mg/day



# Pharmacological Interventions

- **Cannabinoids:** some benefits in cancer & AIDS  
Nabilone 0.1 mg bid- 0.25 mg qid  
SE: Dysphoria, hypotension,  
tachycardia
- **Alcohol:** appetite stimulant
- **Androgens:** currently being studied  
effectiveness not clear



# Dyspnea

- Most frightening symptom for patients, families & health care providers
- One of the most poorly understood areas of palliative care
- Experience may not correlate with any measures of severity OR perceptions of loved ones
- Variable prevalence
- Assess importance to quality of life: ask about exercise tolerance, activities



# Causes of Dyspnea

- Pulmonary causes
- Airway obstruction
- Cardiac causes
- Anemia
- Muscle weakness
- Intra abdominal process
- Psychological



# Dyspnea — Treatment

- Exacerbated by anxiety of dying patient and family members
- Educate:
  1. Experience may not equal perception
  2. Etiologies
  3. Changes in respiratory patterns may not equal dyspnea
  4. Drugs will remove perception of dyspnea but may not alter respiratory pattern
- Non-pharmacological & pharmacological



# Non-Pharmacological Interventions

- Avoid exacerbating activities & be sensitive to sense of isolation
- Normalize emotional responses to dyspnea
- Limit people in room
- Reduce room temperature, maintain humidity
- Open window & allow to see outside
- Use a fan
- Avoid irritants e.g. smoke
- Elevate head of bed
- Relaxation therapy



# Pharmacological Interventions

- **Oxygen:** may help even not necessary by pO<sub>2</sub> or Sats
- **Opioids:** venodilators, sedatives  
decreases sensitivity of ribcage muscles  
does not increase pCO<sub>2</sub>  
intermittent therapy if symptoms intermittent  
nebulized → bronchospasm → not indicated
- **Benzodiazepines/Anxiolytics:**  
decrease thoraco-abdominal response  
decrease anxiety





# Pharmacological Interventions

- Cannabinoids – Nabilone: bronchodilator  
sedative/euphoria  
good for CO<sub>2</sub> retainers
- Steroids: not helpful in all causes of dyspnea  
use for bronchospasm, SVC obstruction,  
lymphangitic carcinomatosis, tracheal obstruction
- Phenothiazines/Butyrophenones: CPZ
- Heliox: improves laminar flow
- Racemic Epinephrine: use for upper airway  
obstruction



# Hemoptysis

- Ranges from streaking of sputum to massive bleeding > 200 cc/24 hrs
- Frightening
- Thankfully rare!
- Etiologies: tumor, bronchitis, pneumonia, pulmonary embolism, low platelets, coagulopathy
- If massive : MD at bedside  
Opioids/ Benzodiazepines  
Hide with towels



# Nausea/Vomiting

- Nausea: caused by stimulation of GI lining, chemoreceptor trigger zone in base of fourth ventricle, vestibular apparatus or cerebral cortex.
- Vomiting: a neuromuscular reflex centered in the medulla oblongata
- Mediators: serotonin, dopamine, acetylcholine, histamine
- Origin in cerebral cortex = learned response



# Etiologies of Nausea/Vomiting

1. Metastases
2. Meningeal irritation
3. Movement
4. Mentation
5. Medications
6. Mucosal irritation
7. Mechanical obstruction
8. Motility
9. Metabolic
10. Microbes
11. Myocardial



# Nausea/Vomiting — Treatment

## Non- Pharmacological:

- Relaxation/Cognitive Training
- TENS/Acupuncture



# Nausea/Vomiting — Treatment

## Pharmacological

- Dopamine  
Antagonists: 1<sup>st</sup> Line
- Histamine  
Antagonists
- Anticholinergics
- Serotonin Antagonists
- Prokinetic Agents
- Antacids
- Cytoprotective agents
- Steroids
- Cannabinoids
- Benzodiazepines



# Bowel Obstruction

- Nausea & vomiting: accumulation of intraluminal fluid and ineffective/altered peristalsis
- Colicky abdominal pain and bloating
  
- Rx: decrease fluid secretions into gut lumen
  1. Anticholinergic drugs
  2. Somatostatin analogues –
    - octreotide 100 ug q8-12 hrs
    - 10 ug/hr IV infusion



# Constipation

Presents as:

- pain
- bloating,
- nausea, vomiting
- overflow incontinence
- tenesmus
- fecal impaction
- bowel obstruction





# Etiologies of Constipation

- Drugs
- Metabolic
- Diet
- Motility
- Spinal cord compression
- Mechanical obstruction
- Dehydration
- Autonomic dysfunction
- Ileus



# Constipation — Treatment

- Rectal exam to detect: stool mass, fecal impaction, hypotonia
- Treatment of causes not appropriate in advanced illness
- Tailor investigations and treatment to stage of illness



# Constipation — Treatment

## Non-Pharmacological:

- Scheduled toileting
- Position: sit up
- Encourage fluid intake in not in advanced stages of illness
- Avoid bulk agents e.g bran → may precipitate obstruction



# Constipation — Treatment

## Pharmacological

- Stimulant laxatives
- Osmotic laxatives
- Detergent laxatives (stool softener)
- Prokinetic agents
- Enemas: lubricant stimulants  
large volume enemas



# Diarrhea

- More than 3 loose stools/ 24-hour period
- Less common than constipation
- If occurs > 3 weeks = chronic
- At EOL commonly due to overuse of laxatives or infection/bacteria or Candida overgrowth
- May lead to: dehydration,  
malabsorption,  
fatigue,  
hemorrhoids,  
perianal skin breakdown



# Etiologies of Diarrhea

- Drugs
- Infection
- Enteral feeds
- Partial bowel obstruction
- Overflow incontinence
- Malabsorption
- Emotional, psychological stress
- GI bleeding
- Radiotherapy
- Tumor



# Non-Pharmacological Interventions

- Rehydration, electrolyte correction
- Avoid milk, gas forming foods
- Hold laxatives
- Consider bulk agents such as bran but use with caution



# Pharmacological Interventions

- Adsorbent – kaolin, attapulgite
- Mucosal prostaglandin inhibitors – ASA,  
mesalazine,  
bismuth
- Opioids – codeine, morphine, diphenoxylate,  
loperamide
- Somatostatin





# Fluid Balance/Edema

- Hypoalbuminemic due to cachexia/anorexia as illness progresses
- Venous congestion
- Lymphatic congestion
- Worse with artificial hydration



# Non-Pharmacological Interventions

- Limit fluid intake
- Increase intake of salty foods
- Elevate feet when sitting
- TEDS stockings to improve venous return
- Watch for skin breakdown



# Pharmacological Interventions

- Diuretics
- Metolazone
- Spironalactone
  
- Watch electrolytes



# Skin Ulcers

- Skin care is poorly taught
- Often relegated to nursing staff
- Can cause: significant pain  
isolation  
odors  
infections
- Management is preventive
- Team approach



# Skin — Practical aspects

- Keep skin clean and dry
- Avoid iodine containing solutions
- Protect pressure points with dressings
- Use draw sheets to move/turn patient
- Use foam pads (not donuts)
- Special mattresses – air or air flotation



# Dressings

Three general types:

- Alginates: exudative bleeding wounds
- Hydrogels: low exudate, necrotic, leg ulcers
- Hydrocolloids: pressure areas, exudates. leg ulcers



# Pressure Ulcers

- Stage I: precursor stage – red, blanches with pressure
- Stage II: does not blanch, excoriated, vesiculation, epidermal breakdown
- Stage III: full thickness skin loss, not extending into subcutaneous tissue, serosanguinous drainage
- Stage IV: ulcer into subcutaneous fat, deep fascia, destruction of muscle, osteomyelitis



# Pressure Ulcers

- Risk factors: CHF, atrial fibrillation,  
Myocardial ischemia  
Peripheral vascular disease  
Anemia,  
Malnutrition,  
Altered level of consciousness,  
Hypoalbuminemia
- Causes: gravity, irritation by sweat, urine, feces,  
perspiration, wound/fistula drainage





# Local Ulcer Treatment

- Stage I & II: polyurethane film
- Stage III: hydrocolloid or calcium alginate
- Stage IV: hydrocolloid  
hydrogel  
enzymatic  
polysaccharide dantromers



# Odors

- Result of infection, poor hygiene
- Treat superficial infections with topical metronidazole or silver sulfadiazine
- If spread to soft tissue consider systemic metronidazole
- Non-pharmacological Rx:
  1. open windows/doors
  2. kitty litter/activated charcoal in pan under bed
  3. burning candles
  4. cup of vinegar in room



# Sleep Disturbances

- Caused by: Anxiety  
Grief  
Pain  
Uncontrolled symptoms  
Fears of future
- Emotional and psychological support from health care team may be insufficient
- May exacerbate asthenia and achievement of symptom control
- Sleep history to guide Rx



# Non-Pharmacological Interventions

- Regular schedule
- Naps OK but avoid sleeping all day
- Control symptoms
- Avoid mental stimulation AND distress at night
- Increase daytime physical activity
- Relaxation therapy, music, imagery
- Avoid stimulants, alcohol, steroids  
metamphetamines at night
- Extra bedding in case of cold



# Pharmacological Interventions

- Antihistamines: rapid tolerance  
anticholinergic SE
- Benzodiazepines: watch for delirium
- Tricyclic antidepressants or sedating ones
- Neuroleptics: esp. if “sun-downing” a problem