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/cachexia
  - 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 end of life
- 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 not relevant and investigations may be inappropriate

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
- Symptom diary
- Rating symptoms on a scale (ESAS/PPS/KPS)
- 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 (occupational/physical therapy consult)
- Change medications and/or times
- Daytime rest and effective sleep at night

Pharmacological Management of Asthenia

- Among the most difficult symptoms to treat
- Steroids: mechanism not clear –? Euphoria
  dexamethasone 2-4 mg po BID
  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: tremulouness, anorexia, tachycardia, insomnia &myocardial ischemia

Anorexia/Cachexia Syndrome

- Weight loss, anorexia, fatigue, chronic nausea
- Inflammatory process, loss of fat and muscle tissue
- Very common in advanced illness
- Frequently associated with asthenia
- May be seen as sign of “failure” or “giving up”
- Increased nutrition often does NOT reverse or improve 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 contributing to secondary cachexia:
    1. Nausea/vomiting
    2. Anxiety
    3. Pain
    4. Constipation/diarrhea

- If no specific cause found, treat anorexia 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 (Appetite Stimulation)

- Steroids: mechanism not clear–? Euphoria/ PG inhibition
  dexamethasone 2-4 po mg BID
  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

- Mirtazapine (Remeron): 15-30 mg qhs
- Androgens: currently being studied
  effectiveness not clear
- No evidence for survival benefit or increase in lean muscle mass

Dyspnea

- Most frightening symptom for patients, families and healthcare 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 and allow to see outside
- Use a fan gently blowing across face
- Avoid irritants, e.g. smoke
- Elevate head of bed
- Relaxation therapy

Pharmacological Interventions

- Oxygen: may help even if not necessary by pO2 or Sats

- Opioids: venodilators, sedatives
  decreases sensitivity of ribcage muscles
  acts centrally to decrease perception of dyspnea
  does not increase pCO2
  intermittent therapy if symptoms intermittent
  nebulized → bronchospasm→ not indicated

- Benzodiazepines/Anxiolytics:
  decrease anxiety
  decrease thoraco-abdominal response

Pharmacological Interventions

- Steroids: not helpful in all causes of dyspnea
  use for bronchospasm, SVC obstruction, lymphangitic carcinomatosis, tracheal obstruction
- Thoracentesis, pleurodesis, paracentesis
- Palliative radiotherapy if mass lesion
- Inhaled bronchodilators if obstructive airway component

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 iv/sc push
- Hide with dark 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 (anticipatory nausea)

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
- ? Evidence of benefit

Nausea/Vomiting — Treatment

Pharmacological

- Dopamine Antagonists: 1st 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 (buscopan, scopolamine)
    2. Antiemetic (haloperidol, avoid metoclopramide if colicky pain)
    3. Analgesia (opioid)

Bowel Obstruction (con't)

3. Antisecretory –

   octreotide 100 ug q8-12 hrs or 10 ug/hr IV infusion

4. steroid

- minimize use of NGT

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 if 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
- Opioid antagonist (methylnaltrexone) if opioid-induced (not available in Canada)

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
  - electrolyte imbalance

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
- Octreotide

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

- Benzodiazepines: watch for delirium
- Tricyclic antidepressants or sedating ones e.g. trazadone)
- Neuroleptics: esp. if "sundowning" a problem