



End-Of-Life Care

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Purpose

The purpose of this continuing nursing education course is to provide healthcare professionals with a palliative care perspective and knowledge to manage symptoms commonly experienced at the end of life.

Objectives

After successful completion of this course, you will be able to:

1. Explain the principles of symptom management at end of life.
2. Describe the assessment of symptoms commonly encountered at end of life.
3. Explain the pharmacologic and non-pharmacologic interventions commonly used at end of life.
4. Discuss physical, psychosocial, emotional, and spiritual issues at end of life.
5. Describe the patient's progression toward death and appropriate interventions during the last months, weeks, days, and hours of life.
6. Identify the components of a quality end-of-life experience.
7. Identify the tasks of grieving.

Introduction

You Matter Because You Are You

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

— Dame Cicely Saunders, nurse, physician and writer, and founder of the modern-day hospice movement (1918 - 2005).

All Americans deserve quality care at the end of life – it's a fundamental part of living (National Hospice and Palliative Care Organization (NHPCO), 2016).

Heart disease, cancer, and chronic lung disease are the main causes of the death in the United States. Death from these causes is neither sudden nor unexpected yet the rate of hospice use remains low. Despite all the technological advances in health care, patients, families and providers are still dissatisfied with end-of-life-care (Dans & Sheldahl, 2015).

End of Life Care

"Life is pleasant. Death is peaceful. It's the transition that's troublesome."

— Isaac Asimov, American science fiction novelist & scholar (1920 - 1992).

End-of-life care begins with advanced planning. Most of the American population have not discussed their end-of-life care with loved ones and do not have their wishes documented in Advanced Directives. This occurs because the patient, family, or clinician wait for the other person to begin the conversation. Thus, confusion, anger, and stress occur during this most difficult time. People need to discuss their preferences, have the discussion frequently, and have these preferences written down.

A poll of Americans revealed that 88% of adults prefer to die at home surrounded by loved ones and free of pain (NHPCO, 2016). During this time, there are two services that can be provided to make this happen for the chronically ill and terminally ill. These services are:

- Palliative Care: Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves

addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice (NHPCO, 2016)

- Hospice Care: The model for quality compassionate care for people facing a life-limiting illness; providing medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes and support for the family (NHPCO, 2016).

While many use palliative care and hospice care interchangeably, there is one defining point that makes them separate services. The Centers for Medicare and Medicaid Services (CMS) require that the terminally-ill patient receiving HOSPICE care have a prognosis of six months or less. Palliative Care may be implemented for symptom relief for any patient with chronic symptoms. Palliative Care may be implemented for the terminally-ill patient for symptom relief prior to receiving Hospice Care.

Did You Know?

Palliative care and Hospice care are available to pediatric patients

Palliative Care

Palliative care can begin early during treatment for management of pain, difficulty breathing, swallowing, and in conjunction with other disease treatment. This care can be delivered in any setting including hospitals, skilled nursing facilities, and the patient's home. It's an organized continuum of care delivered by an interprofessional team including physicians, nurses, social workers, chaplains, and pharmacists. The goal is to provide patient-centered, family-oriented, evidence-based care at the end-of-life or for chronic symptom management in the chronically ill (IOM, 2014).

Palliative care differs from the acute care model in that it:

- Focuses on comfort and managing symptoms
- Views the unit of care as the patient and family
- Operates in an interprofessional framework
- Addresses psychosocial and spiritual aspects as well as physiological (whole-person oriented)
- Treats the underlying cause of symptoms when possible

Hospice Care

Hospice cares for more than 1.65 million patients annually. While hospice care begins when the terminally-ill patient has a prognosis of six months or less, there is not a limit to hospice care services. According to Medicare, the patient is covered for two 90-day periods (six months) and then indefinitely. However, the physician must certify that the patient meets the criteria every 60 days (NHPCO, 2016).

Hospice care can be implemented in a healthcare facility or at home. Many hospices have respite care for the care-giver and hospice facilities.

End-of-Life Symptom Management

Common End-of-Life Symptoms

- Powerlessness
- Anorexia and Cachexia
- Fatigue
- Pruritus

- Alterations in oral mucosa
- Nausea and vomiting
- Ascites
- Dyspnea
- Upper Airway Congestion
- Pain
- Constipation
- Agitation and delirium

Powerlessness

Patients may experience any number of symptoms at the end-of-life and they often feel powerless to control what is happening to them. This is evident in that many patients express feelings of having no influence over the situation or outcome. So, it is important to keep some basic interventions in mind when trying to manage end-of-life symptoms to facilitate the patients' participation in their care.

1. Determine the patient's usual response to limited control situations
2. Determine the patient's usual locus of control (i.e., believes that influence over his or her life is exerted by luck, fate, powerful persons [external locus of control] or that influence is exerted through personal choices, self-effort, self-determination [internal locus of control])
3. Support patient's physical control of the environment by involving him or her in care activities; knock before entering room if appropriate; ask permission before moving personal belongings
4. Inform the patient that, although an activity may not be to his or her liking, it is necessary. This gives the patient permission to express dissatisfaction with the environment and the regimen
5. Provide therapeutic rationale for the treatment plan, reinforce the explanations, and clarify misconceptions
6. Include the patient in care planning by encouraging participation and allowing choices wherever possible (e.g., timing of personal care activities; deciding when pain medicines are needed)

Allowing the patient to be as independently as possible will give the person a sense of power over the situation.

Anorexia and Cachexia

Anorexia is described as the generalized loss of appetite and inability to take in nutrients and is common in advanced illness and at end of life especially among the elderly (Bruera & Dev, 2015).

Family members and caregivers experience:

- Loss of the ability to nurture in the usual way of offering favorite foods.
- Feeling hopelessness and giving up.

Cachexia, or wasting syndrome, results in weight loss and wasting due to inadequate intake and/or absorption of nutrients. Cachexia often occurs as a part of the dying process and represents psychosocial loss for patients and families. It is a symptom that cannot be ignored (Bruera & Dev, 2015).

Cachexia also causes:

- A drastic alteration in body image
- A loss of socialization associated with eating

- An adjustment to dramatic decrease in body mass
- A symptom that cannot be ignored

Anorexia and Cachexia: Causes

Causes of anorexia and cachexia in palliative care patients include:

- Pain
- Constipation
- Alterations in oral mucosa
- Dysgeusia (change in taste perception)
- Altered mental status
- Medications
- Natural disease progression
- Natural aging process
- Chronic fatigue
- Nausea
- Depression
- Gastroparesis

Sometimes it can be very difficult to pinpoint a cause, because there are so many, and the patient may be experiencing several of them at once.

Anorexia and Cachexia: Management

There are a variety of interventions to assist the palliative care patient with anorexia and cachexia (Bruere & Dev, 2015).

The patient should be encouraged to:

- Eat at the dining table (if possible) with family
- Plan frequent small meals that are calorically dense
- Prepare meals that require little preparation
- Rest before meals

In some cases, medications may be helpful to stimulate the patient's appetite, these include:

- Progestin
- Megestrol acetate (Megace)
- Glucocorticoids (dexamethasone, methylprednisolone, betamethasone)
- Cannabinoids (marijuana)

There is no evidence to support the use of nutritional support, such as total parenteral nutrition (TPN) or enteral nutrition, in the palliative care patient. It rarely halts the progression of the disease and may add burden to the dying process as issues regarding discontinuation may arise (Bruera & Dev, 2015).

Test Your Knowledge

The cause of anorexia at end of life can be easily identified.

True

False

Rationale: Sometimes it can be very difficult to pinpoint a cause, because there are so many, and the patient may be experiencing several of them at once.

Fatigue

Fatigue is a subjective symptom in which the patient feels tired, weak, and mentally exhausted and is the most common symptom seen in palliative care patients. This symptom is one of the most undertreated and underreported (Bruera & Yennurajalingam, 2014). The family might interpret this as giving up and push the patient beyond what he or she can respond to. While it is important to conserve energy in fatigued patients, they benefit from activity.

Fatigue: Causes

Fatigue in the palliative care patient is often multi-factorial. Causes include:

- Disease progression
- Common morbidities (renal, cardiac, diabetes)
- Lack of sleep
- Medications (side effects, cumulative effects, and drug interactions)
- Anemia
- Infection
- Hypoxemia
- Dehydration
- Pain
- Depression
- Nausea
- Anorexia
- Dyspnea

Fatigue: Management

Initial management of the patient with fatigue includes identifying and treating the underlying cause. Both pharmacologic and nonpharmacologic interventions are available to assist with the management of fatigue in the palliative care patient.

Medications may be of benefit to the patient. These include:

- Glucocorticoids (dexamethasone, methylprednisolone)
- Psychostimulants (dextroamphetamine, methylphenidate, modafinil)
- Testosterone replacement (in men with low testosterone)
(Bruera & Yennurajalingam, 2014)

There are a variety of nonpharmacologic interventions to assist the palliative care patient with fatigue. The patient should be encouraged to:

- Schedule activities at times of greatest energy
- Maintain a regular activity schedule
- Get assistance from volunteers, family, and friends
- Engage in moderate exercise if able to tolerate it
- Participate in yoga classes
- Initiate routine sleep hygiene measures

- Manage stress
(Bruera & Yennurajalingam, 2014)

Pruritus

Pruritus may not be the most prevalent symptom in the palliative care patient, it can cause considerable discomfort and has a major impact on patients' quality of life (Crossroads Hospice & Palliative Care, 2018).

There are four types of pruritus:

- Proprioceptive – itch originates in the skin
- Neuropathic – itch originates in the afferent sensory pathways
- Neurogenic – itch originates in the central nervous system
- Psychogenic – itch is associated with a psychiatric disorder

Pruritis: Causes

Causes of pruritus are not completely understood. However, pruritus is associated with the following conditions:

- Anemia
- Cholestasis
- Chronic kidney disease
- Cirrhosis
- Diabetes
- Hepatitis
- Hepatoma
- Leukemia
- Lymphoma
- Multiple myeloma
- Paraneoplastic syndrome
- Polycythemia
- Thyroid disease

(Crossroads Hospice & Palliative Care, 2018)

Pruritus: Management

Both pharmacologic and nonpharmacologic interventions are available to assist with the management of pruritus in the palliative care patient.

- Whenever possible treat the underlying condition
- Utilization of medications with antihistamines
- Moisturizers added to the bath or placed on the skin
- Reduce the amount of bathing, use tepid water, and mild, unscented soap
- Wear loose, no-irritating clothes
- Maintain a cool, humidified room
- Avoid scented perfumes and lotions

Alterations in Oral Mucosa

In the palliative care patient alterations in the oral mucosa can be very problematic as they interfere with the patient's ability to eat and thus contribute to worsening anorexia and fatigue. Patient who have undergone radiation are at high risk for developing problems with the oral mucosa. Other contributing factors include poor nutrition, poor dental hygiene, ill-fitting dentures and tobacco use (Radvansky, Pace, & Siddiqui, 2013).

Common alteration in the oral mucosa of the palliative care patient include:

- Xerostomia (dry mouth)
- Oral Mucositis (stomatitis)

Alterations in Oral Mucosa: Management

Management of both xerostomia and stomatitis is aimed at symptom relief. Both conditions can be extremely uncomfortable for the patient. The choice of intervention should be left up to the patient, as each patient's response to the different interventions will vary.

Interventions for xerostomia include:

- Encourage frequent meals
- Encourage proper oral hygiene
- Drink plenty of water or suck on ice chips
- Use artificial saliva to mimic the properties of real saliva (lubricating, hydrating, antimicrobial)
- Stimulate salivation with moistening agents or sialagogues (pilocarpine)
- Chew sugarless gum or suck on hard candies and mints

(Radvansky, Pace, & Siddiqui, 2013)

Interventions for stomatitis include:

- Administration of pain medications
- Use of mouth rinses:
 - "Miracle mouthwash" or "magic mouthwash" (e.g., aluminum hydroxide, diphenhydramine, viscous lidocaine)
 - Saline rinses
 - 2% viscous lidocaine
- Provide around-the-clock mouth care
- Avoid spicy foods

(Radvansky, Pace, & Siddiqui, 2013)

Test Your Knowledge

Which of the following interventions may be of benefit for the patient with xerostomia?

- Limit the patient's oral intake
- Have the patient swish and spit with "magic mouthwash" once a day
- Encourage the patient to chew sugarless gum**
- Restrict the patient's diet to protein sources only

Rationale: Interventions for xerostomia include:

- Encourage frequent meals
- Encourage proper oral hygiene

- Drink plenty of water or suck on ice chips
- Use artificial saliva to mimic the properties of real saliva (lubricating, hydrating, antimicrobial)
- Stimulate salivation with moistening agents or sialagogues (pilocarpine)
- Chew sugarless gum or suck on hard candies and mints

Nausea and Vomiting

Nausea is the unpleasant sensation of the need to vomit while vomiting is the forceful expulsion of gastric contents. Each can be experienced separately, or they can be experienced together. Every patient experiences them differently (Nunn, 2014).

Severe, intractable nausea limits the time that you can spend around other people and is physically very draining. It affects one's ability to take in nutrients and contributes to worsening anorexia and fatigue.

People begin to struggle and question: "Why do I suffer in this way?" and "Why do people even care about me anymore?" For patients who have suffered with this symptom for a long time, it has severely impacted their ability to enjoy a good quality of life.

Two of the most debilitating symptoms seen in the palliative care patient is nausea and vomiting and it occurs in 17 – 49% of the patients (Kelly & Ward, 2013).

Nausea and Vomiting: Causes

There are a wide assortment of causes of nausea and vomiting. The vomiting center is in the brainstem and it receives input from a variety of sources via the emetic pathways producing nausea (Kelly & Ward, 2013).

Inputs to the vomiting center are as follows as well:

Sources of Stimulation via the Emetic Pathways	Biochemical Afferents Released in Nausea
Vagal Afferents <ul style="list-style-type: none"> ▪ Gastric stasis ▪ Distortion of GI tract (constipation, intestinal obstruction) ▪ Drugs (NSAIDS, iron supplements, antibiotics, cytotoxics, steroids, anticholinergics, opioids) ▪ Ascites ▪ Liver metastases ▪ Retroperitoneal cancer ▪ Peptic ulcers 	Vagal Afferents <ul style="list-style-type: none"> ▪ Acetylcholine ▪ Histamine ▪ Serotonin
Pharyngeal Afferents <ul style="list-style-type: none"> ▪ Irritation in pharynx: sputum, coughing, candida 	Pharyngeal Afferents <ul style="list-style-type: none"> ▪ Glossopharyngeal and vagal nerve stimulation
Vestibular System <ul style="list-style-type: none"> ▪ Motion sickness ▪ Medications ▪ Brain tumors 	Vestibular System <ul style="list-style-type: none"> ▪ Acetylcholine ▪ Histamine
Midbrain Afferents <ul style="list-style-type: none"> ▪ Anxiety, stress ▪ Sights, sounds, taste ▪ Increased intracranial pressure ▪ Brain tumors 	Midbrain Afferents <ul style="list-style-type: none"> ▪ Acetylcholine ▪ Histamine
Chemotherapy Trigger Zone (CTZ) <ul style="list-style-type: none"> ▪ Medications (opioids, cytotoxics, antibiotics) ▪ Chemicals ▪ Toxins ▪ Metabolic (organ failure, hypercalcemia, hyponatremia) 	Chemotherapy Trigger Zone (CTZ) <ul style="list-style-type: none"> ▪ Dopamine ▪ Serotonin (also released in the gut) ▪ 5-HT₃₊₄

Nausea and Vomiting: Management

There are several medications used in the treatment of nausea. It's important to identify and treat the underlying cause first if possible. Each anti-emetic medication is most useful in combating causes of nausea.

Medication	Blocks	Cause-specific Uses
Dexamethasone	Unclear as to action	Reduces swelling, useful in brain tumor
Diphenhydramine	Histamine	Idiopathic and opioid-induced nausea, vestibular causes, obstruction, malignant bowel obstruction, increased intracranial pressure
Haloperidol	Dopamine	Chemical/metabolic, opioid-induced nausea, malignant bowel obstruction, useful with patients with dementia who respond poorly to benzodiazepines, relieves agitation
Metoclopramide	Dopamine, 5-HT ₃₊₄	Gastric stasis, ileus, opioid-induced nausea Caution: if there is an obstruction, increasing motility may cause an intestinal rupture
Ondansetron	5-HT ₃	Prevention of radiation- and chemotherapy-induced nausea and post-operative nausea NOT a first-line medication unless nausea is intractable
Prochlorperazine	Dopamine, Histamine, Acetylcholine Highly effective because it blocks multiple substances well.	
Anticholinergics (scopolamine) with caution, to avoid drowsiness, confusion, urinary retention and dry mouth, especially with elderly patients		Obstruction, increased gastric secretions, increased intracranial pressure

Test Your Knowledge

Mr. D has end-stage cardiac disease. He suffers from intermittent chest pain and extreme discomfort in his lower extremities due to bilateral pedal edema. His physician orders an opioid for the pain. The following day, Mr. D reports that his pain is improved, but he cannot eat due to moderate nausea. Which drug will be MOST effective in treating Mr. D's nausea?

- Diphenhydramine (Benadryl®)
- Haloperidol (Haldol®)**
- Metoclopramide (Reglan®)

d. Ondansetron (Zofran®)

Rationale: *Haloperidol works quite well for opioid-induced nausea. With a little help from an anti-emetic, it should resolve within a few days. Benadryl® is also a good choice. If Mr. D were 85-years-old, we might not choose Benadryl®. Reglan® can be used even for opioid-induced nausea. Zofran® is a preventive drug.*

Nausea and Vomiting: Non-pharmacologic Interventions

Several non-pharmacologic interventions may be of benefit for the palliative patient with nausea and vomiting. These interventions include (Kelly & Ward, 2013):

- Maintain a cool, odor-free environment. A fan may help to facilitate this
- Modify the patient's diet – bland, not spicy.
- Offer small, simple meals. Carbohydrates are often tolerated better
- Cool, carbonated drinks are often tolerated better than hot or noncarbonated drinks
- Treat constipation if present – common at end of life
- Correct electrolyte imbalance if known – the patient may have decided against labs. Assess for symptoms of electrolyte imbalance
- Consider switching opioids if transient nausea does not subside – switch from morphine to hydromorphone or oxycodone
- Provide an open view, without clutter.
- Ensure the patient has access to a large bucket or bowl, tissues and water
- Offer regular mouth care

Ascites

Ascites can be a troublesome symptom at end of life. Ascites refers to fluid that accumulates within the peritoneal cavity. Approximately 85% of ascites is associated with patients with cirrhosis and resulting portal hypertension. However, 7% to 10% of patients with malignancies develop ascites. Pathologies such as liver disease, abdominal cancers, and sometimes congestive heart failure cause compression of lymph or portal systems. This mechanical interference with drainage causes fluid to accumulate. Other potential causes include pancreatitis, nephrotic syndrome, and hepatic venous obstruction (Kistler, 2015).

In addition to increased abdominal girth, patients experience:

- Nausea
- Bloating
- Pain
- Heartburn
- Dyspnea
- Orthopnea

Ascites: Management

Management of the palliative patient depends on the underlying cause. Patient with ascites related to portal hypertension may be responsive to diuretics. However, patients may become refractory to these medications at end of life. Up to 90% of the patient obtain relief with a paracentesis. If a patient requires continuous draining of the fluid, a drainage catheter can be placed to allow for continuous or intermittent drainage and promote patient comfort (Kistler, 2015).

Test Your Knowledge

Mrs. J, age 66 years, has ovarian cancer with liver metastasis. She is receiving hospice services. She can still ambulate occasionally but has developed extensive ascites with increasing symptoms of dyspnea, nausea, and heartburn. Which intervention do you expect to be most effective?

- a. Administer morphine liberally since patient is in hospice care
- b. Restrict fluids, provide good skin care, and encourage frequent repositioning
- c. Facilitate placement of an abdominal drainage catheter for intermittent drainage**
- d. Obtain an order for a diuretic

Rationale: Management of the palliative patient depends on the underlying cause. Patient with ascites related to portal hypertension may be responsive to diuretics. However, patients may become refractory to these medications at end of life. Up to 90% of the patient obtain relief with a paracentesis. If a patient requires continuous draining of the fluid, a drainage catheter can be placed to allow for continuous or intermittent drainage and promote patient comfort (Kistler, 2015).

Dyspnea

Dyspnea is the sustained unpleasant sensation of breathlessness and uncomfortable awareness of breathing. It is a progressively debilitating symptom that has a big impact on the patient's quality of life. If dyspnea is not well managed a patient can develop a dyspnea crisis. A dyspnea crisis is "sustained and severe resting breathing discomfort that occurs in patients with advanced, often life-limiting illness and overwhelms the patient and caregivers' ability to achieve symptom relief. The patient with dyspnea may or may not exhibit the signs of hypoxemia and as a result oxygen saturation is not a reliable measure of dyspnea (The American Thoracic Society (ATS), 2013).

Dyspnea: Causes

Dyspnea can be caused by a wide variety of conditions including:

- Chronic obstructive pulmonary disease (COPD)
- Pulmonary fibrosis
- Acute and chronic heart failure,
- Pulmonary embolism
- Cancer (primarily lung cancer)
- Pneumonia
- Anemia
- Pneumothorax
- Radiotherapy
- Anxiety

Dyspnea: The Patient's Perception

Dyspnea, like pain, is a subjective symptom. That means that the patient is the only one who is an expert. Sometimes patients who exhibit signs associated with dyspnea are not actually having trouble breathing. Thus, to effectively assess interventions to lessen dyspnea, the patient must be asked about his or her degree of breathlessness.

Sometimes our observations might fool us. We might think a person looks dyspneic. But the patient may not report dyspnea because he has compensated for so many years.

Chronic lung patients who have had the disease for 10-30 years may have learned to accommodate. When the patient has a dyspnea crisis, listen to the patient and ask: "Is your dyspnea mild, moderate, or severe?"

Dyspnea: Management

Pharmacological Interventions

Many different medications may be useful, depending upon the underlying disorder and/or cause of dyspnea.

- Patients with COPD should be on inhaled beta-2 agonists and anticholinergic agents.
- Patients with asthma should be on inhaled steroids
- Patients with heart failure should be on diuretics, beta-blockers, and angiotensin-converting enzyme inhibitors.

Primarily opioids are also used to manage dyspnea as they blunt the central perception of breathlessness and lower the drive to breathe. Opioids may be administered via any appropriate route as needed. A typical dose range is 2.5 to 7.5 mg every 4 hours which can be titrated higher as needed.

Opioids may be combined with an anti-anxiety medication, such as lorazepam or alprazolam. Combined, these medications can make a huge difference in that they facilitate the patient's ability to relax, take in deep breaths, or just relieve fear.

Non-pharmacologic Interventions

Monitoring the patient's oxygen saturation will not benefit the patient as dyspnea is a subjective sensation.

There are several nonpharmacologic interventions for dyspnea. These include:

- Position the patient in High Fowler's position or tripod position (leaning forward resting on elbows) or standing and leaning against a wall with arms overhead
 - The tripod position assists the patient who has emphysema or chronic bronchitis in using accessory muscles to push air out. A patient who has pulmonary fibrosis and has difficulty getting air into the lungs and bronchioles may lean back in a kind of uncharacteristic way and even lay flat on the back to pull air in. Don't be surprised if the patient is trying to adjust himself to find the best way to reach some level of comfort.
- Administer oxygen therapy
 - Some patients with chronic lung disease have received oxygen for years. Patients who have pulmonary fibrosis may require much higher doses of oxygen than a patient who has emphysema or chronic obstructive pulmonary disease.
- Provide the patient direct air flow from fan
 - Cool air flow across the face has been shown to decrease the sensation of breathlessness.
- Reassure the patient and encourage the use of relaxation techniques.
 - Encourage the patient to use different breathing techniques such as slow-breathing, pursed-lip breathing and/or diaphragmatic breathing.
 - Help patients train their breathing

(ATS, 2013)

Test Your Knowledge

Which of the following interventions has been shown to be of benefit to the palliative care patient with

dyspnea?

- a. Place the patient in supine with the head of the bed less than 30°
- b. Limit oxygen administration to less than 2 L/min
- c. **Place a fan near the patient's face**
- d. Monitor the patient's oxygen saturation level

Rationale: Cool air flow across the face has been shown to decrease the sensation of breathlessness

Test Your Knowledge

Mr. D has advanced lung cancer and a history of congestive heart failure with recurring dyspnea. His current medication regimen includes digoxin and furosemide. After assessing the patient, what is the first thing you will do?

- a. Obtain an order for low-dose morphine
- b. Request an order for pulse oximetry
- c. **Ask him if he has taken his medication.**
- d. Inform him that this is expected disease progression

Rationale: Asking the patient if he's taken his medication is the first thing to do, simply because we must be sure that the patient is medically managing and maximizing the use of prescribed medication first. If not, we may have to administer those medications before proceeding with other interventions.

Upper Airway Congestion

Commonly referred to as the "death rattle," upper airway congestion can be an extremely distressful symptom. It is often seen during the last day or two of the patient's life and is a strong predictor of death (Nunn, 2014).

It is important to educate families and caregivers that the patient simply has lost the ability to swallow, leading to a collection of mucous or saliva at the back of the throat.

Upper Airway Congestion: Causes

Many etiologies can lead to airway congestion at end of life, such as

- Excessive oropharyngeal secretions
- Excessive pulmonary secretions
- Fluid overload
- Decreasing level of consciousness
- Absent or suppressed gag and cough reflexes
- Supine recumbent position
- Inability to swallow

(Nunn, 2014)

Upper Airway Congestion: Management

The best and easiest approach to manage these secretions is to turn the patient or reposition him slightly.

Clean the mouth with a washcloth to remove some of the secretions. The congestion will recur and may require repeated repositioning and cleansing. But a slight repositioning of the head or upper body may help relieve the congestion. It is not necessary to turn completely from one side to the other.

Suction rarely helps because the secretions continue to reoccur. Suction can be very intrusive and uncomfortable for the patient.

Antimuscarinic medications can be used to block the parasympathetic nervous system which ultimately leads to decreased production of secretions in the salivary, bronchial, and gastrointestinal tracts. Medications that are commonly used are:

- Hyoscine hydrobromide
- Glycopyrronium
- Hyoscine butyl bromide
- Atropine 1% eye drops (given sublingually)

Case Study

Laura is an alert 55-year-old with end-stage oat-cell carcinoma. She complains of severe dyspnea due to excessive bronchial secretions. Which do you expect will relieve her discomfort?

- Atropine ophthalmic gtts 1% 1-2 SL Q4H PRN
- Gentle suction to clear her airway

Atropine is more useful to reduce oral secretions. Be sure to advise caregivers to administer SL and not as eye drops. Scopolamine or glycopyrrolate are the best choices. These medications, and atropine as well, are anti-cholinergics administered for their side effects of drying secretions, as adjuvant medications. Don't use suction as this procedure can cause more discomfort and increase secretions.

Pain

Types of Pain

- Nociceptive pain - the pain pathways are normal. Put your finger on a hot stove, the stimulus goes up your arm to your spinal cord to your brain and your brain says, "Ouch, move your finger, that's hot and it hurts." That's a normal pain pathway.
- Neuropathic pain - a nerve pathway has been disrupted, perhaps through resection, amputation, or pressure. Neuropathic pain is not the result of an external cause.
- Somatic pain is musculoskeletal type of pain, bone pain - the framework pain, as opposed to visceral pain. Somatic pain requires NSAIDs or other medications.
- Visceral pain is an organic type of pain, originating in the hollow tubes and organs, such as labor pain, kidney stone pain, and colicky pain. Visceral pain is normally treated quite well and adequately with opioids alone and may not require an adjuvant.

Pain: Management

Opioids are safe and effective ways to manage pain. At end of life, few patients need to use anything other than oral pain medication. It's often the most convenient and the safest. It's familiar and easy for caregivers to administer. The optimal dose for the patient is established through titration.

It is important to note that patients at the end of their lives will require higher doses of medication. They should be given as much medication as necessary to make them comfortable. Are you concerned that by administering large doses of medications may hasten their death? It might; however, your intent is to make the patient comfortable, and decreased respirations or blood pressure is an acceptable consequence at this time of the patient's life.

For chronic and severe pain, around-the-clock dosing, rather than the short-term, immediate-acting preparations are generally used. When extended-release (ER) or sustained-release (SR) preparations, are given a plan to address breakthrough pain should be in place for the times when the ER/SR dose is just not enough.

Pain: Assessment

Managing pain begins with careful assessment. Assessment parameters should include:

- Site
- Intensity
 - Current, best, worst, acceptable
- Quality or type of pain
 - Onset, duration, patterns
 - Most pain will be worse at night simply because of less competing sensory stimuli.
 - Most people report higher levels of pain at night.
- Alleviating factors
- Impact on quality of life
- Accompanying symptoms

Pain and nausea together tend to escalate and accentuate one another in the patient's experience.



(Pasero & McCaffery, 2011)

American Pain Society Guidelines

- Individualize the route, dosage, and schedule
 - Oral is most convenient and safest
- Establish optimal dose through titration
 - Usually begin with immediate-release (IR) to establish lowest effective sustained-release (SR) dose
- Around-the-Clock dosing for chronic, severe pain
- Appropriate IR dosing for breakthrough pain
- Know patient's history of opioid use
 - Both prescription and street drugs
- Assess and reassess patient closely when beginning or changing analgesics
- Use equianalgesic dosing charts when changing to a new opioid or a new route
- Recognize and treat side effects
- Ceiling doses of opioids limited only by unwanted side effects
- Avoid meperidine
- Avoid poly-opioid pharmacy whenever possible

Opioids in Palliative Care

The patient's history of opioid use or lack thereof affects management simply because prescription or street drugs may impact the ability to process pain medication. Even though the patient is no longer actively using, pain receptors in the spinal cord may be adversely affected by substance abuse. Even years down the road, it may cause the patient to need more and more opioids to control pain.

The reason that opioids are so powerful, is that they, especially morphine and oxycodone, are not limited by a ceiling dose like other medications. Meperidine is rarely used in end-of-life care simply because the metabolites produced affect renal and hepatic clearance. It's not a very effective medication at the end of life.

Try to avoid poly-opioid pharmacy. It's best to simplify the opioid to one type rather than having for example, a fentanyl patch, an oxycodone extended-release and a morphine preparation for breakthrough. If possible, stay in the same pharmacological family for the ease of titration and conversion.

The World Health Organization (WHO)- Pain Management Ladder

The WHO developed a three-step ladder for cancer pain relief in adults.

Step 3: Freedom from Cancer Pain

Opioids for moderate to severe pain

+/- Non-opioid

+/- Adjuvant

Step 2: Pain persisting or increasing

Opioids for mild to moderate pain

+/- Non-opioid

+/- Adjuvant

Step 1: Pain Persisting or increasing

Non-opioid

+/- Adjuvant

When pain occurs, prompt medication administration should begin with non-opioids, followed by mild opioids, followed by strong opioids. Adjuvant drugs such as anxiolytics, sedatives, anti-emetics should be given as necessary (World Health Organization, 2018).

Case Study

Mr. G, age 76, is newly admitted to home hospice. His primary caregiver is his 78-year-old wife. He has completed treatment for malignant melanoma with metastasis to his liver, lungs, and lumbar vertebra.

Initial pain assessment reveals a moderate, dull, aching pain in his lumbar area and a sharp, shooting pain radiating down his left leg that keeps him awake at night. His last BM was two days ago. He is oriented x3 but reports increasing difficulty articulating his thoughts and communicating clearly. He reports “feelings of sadness,” a fear of the future, and increasing anxiety.

Discharge orders are as follows:

- 5 mg oxycodone/325 mg acetaminophen (Percocet® 5 mg) two tabs Q4H PRN. Currently taking 12 tablets/24 hours
- Acetaminophen (Tylenol®) 500 mg Q6-8H PRN. Currently taking 1000 mg/24 hours
- Lorazepam 0.5-1.0 mg Q1H PRN Currently not taking this

Test Your Knowledge

What type of pain is Mr. G experiencing?

- Neuropathic and somatic**
- Nociceptive and visceral
- Neuropathic and visceral
- Nociceptive and somatic

Rationale: He describes his pain as dull, aching. That is somatic pain, a musculoskeletal kind of dull pain. And he said sharp pain radiating down his leg. That’s a red flag for neuropathic pain. Words like radiating, tingling, and sharp describe neuropathic pain.

Test Your Knowledge

What is the MOST important medication change to make immediately on the initial admission visit with Mr. G?

- Increase the oxycodone/acetaminophen (Percocet®)
- Add an NSAID
- Stop the extra-strength acetaminophen (Tylenol®)**
- Schedule the lorazepam (Ativan®) around the clock

Rationale: If he is taking Percocet®, he’s already at the maximum ceiling dose for acetaminophen (4 grams/day, for the elderly, 3200 - 2600 mg). It’s very important to be sure that patients aren’t taking Tylenol® on the side, or that they’re double-prescribed with acetaminophen. If the patient’s pain is increasing, we might eventually increase the percocet. However, we are limited because of the acetaminophen dose. An

NSAID or lorazepam might be added later.

Test Your Knowledge

Mr. G reports that his pain is at an intensity level of 6/10 and is unacceptable. You call the physician and he changes the oxycodone/acetaminophen (Percocet®) to an extended-release opioid.

Which opioid will most likely be ordered?

- Morphine or oxycodone without acetaminophen**
- Hydromorphone (Dilaudid®)
- Demerol
- Fentanyl

Rationale: Dilaudid is often the opioid of choice, but not in this situation because no ER form is yet available. Morphine is available in many forms, is easy to titrate, and has been well-researched. Some prescribers might choose to stay with oxycodone instead. Though fentanyl is effective for chronic pain, it is less effective at end of life because the transdermal absorption is slow and is difficult to titrate.)

Converting One Opioid to Another

Mr. G is currently taking 12 tablets daily of oxycodone/acetaminophen (Percocet®) 5 mg. Which morphine order would be recommended to the physician when rotating from the Percocet® to morphine?

- Calculate total 24-hr oxycodone dose used currently:
 - 12 tablets per day X 5 mg oxycodone = 60 mg**
- Convert 24-hr total to equivalent dose of morphine using the equianalgesic chart

Analgesic Opioid Agonist	Equianalgesic Dose		Dosing Interval	
	Oral	IM/SQ/IV	Immediate-Release	Controlled-Release
Morphine	30 mg	10 mg	1-4 hours	8-12 hours
Oxycodone	20 mg	N/A	1-4 hours	8-12 hours

$$\frac{30 \text{ mg morphine}}{x} = \frac{20 \text{ mg oxycodone}}{60 \text{ mg oxycodone}}$$

$$20x = 1800$$

$$x = 90 \text{ mg}$$

- Because of cross-tolerance, initiate the new opioid at $\frac{1}{2}$ - $\frac{2}{3}$ recommended equianalgesic conversion.
 - 90 mg X $\frac{1}{2}$ = 45 mg
 - 90 mg X $\frac{2}{3}$ = 60 mg

Calculating a Breakthrough Dose

Mr. G's prescriber conservatively ordered morphine sulfate extended-release (MS ER) 30 mg Q12H. What is the appropriate morphine sulfate immediate-release (MSIR) breakthrough dose for the new extended-release morphine order?

The breakthrough dose is 10% – 20% of the new 24-hour dose Q1H PRN.

- Calculate 24-hour morphine dose:
 - $30 \text{ mg} \times 2 = 60 \text{ mg}$

Calculate the breakthrough doses

- 10% of 60 mg = 6 mg
- 20% of 60 = 12 mg

Increasing the Breakthrough Dose

As the patient nears the final days and hours of life, his/her pain may escalate. Knowing how to safely increase the dose to meet the pain needs is essential.

Moderate pain: increase the dose by 25%.

- Calculate the total amount of opioid taken in the last 24 hours
 - $60 \text{ mg (ER medication dose)} + 60 \text{ mg (breakthrough)} = 120 \text{ mg}$
 - $\frac{120 \text{ mg}}{4} = 30 \text{ mg}$
 - $30 \text{ mg} + 120 \text{ mg} = 150 \text{ mg/day}$ or 75 mg q 12 hours

Severe Pain: increase the dose by 50%

- Calculate the total amount of opioid taken in the last 24 hours
 - $60 \text{ mg (ER medication dose)} + 60 \text{ mg (breakthrough)} = 120 \text{ mg}$
 - $\frac{120 \text{ mg}}{2} = 60 \text{ mg}$
 - $60 \text{ mg} + 120 \text{ mg} = 210 \text{ mg/day}$ or 105 mg q 12 hours

Recalculate breakthrough:

- Use 10 – 20% of the new 24-hour dose Q1H PRN
 - Moderate pain: 10% of 120 mg = 12 mg or 20% of 120 mg = 24 mg
 - Severe pain: 10% of 210 mg = 21 mg or 20% of 210 mg = 42 mg

Peak Action time for Immediate Acting Medication:

- 15-30 minutes to effect
- 60 minutes to peak plasma level and excretion

Because the body starts to excrete the medication after one hour, the patient will not be over medicated if another dose is given in hourly increments.

Test Your Knowledge

Mr. G is converted to morphine sulfate extended-release 30 mg Q12H PO/SL and morphine sulfate immediate-release 5-10 mg Q1H PRN. Appropriate dosages of Senna and Docusate Sodium were initiated. What additional medication change would be MOST appropriate on this initial visit?

- Resume the Acetaminophen (Tylenol®) to address the bone pain
- Continue the Lorazepam (Ativan®) due to his increased anxiety
- Obtain an order for generic Temazepam (Restoril®) to help the patient sleep at night
- Obtain an order for ibuprofen (Advil®) 800 mg Q8H due to the presence of somatic pain**

Rationale: Obtaining an order for ibuprofen or some other NSAID to address the somatic pain and bone pain to related bone metastasis is MOST important and may produce a dramatic response. A patient may have been on an opioid for months or years and not been given the additional boost of an NSAID. Sometimes within 24-36 hours after a few doses of TID ibuprofen, there's a dramatic difference in pain as the NSAID can boost the effect of the opioid.

Test Your Knowledge

Which instruction is most important to give Mr. G's 78-year-old wife initially?

- a. Count Mr. G's respirations for a full minute at regular intervals
- b. Expect that Mr. G may sleep for an extended period**
- c. Keep a detailed record of pain intensity and breakthrough doses
- d. Observe for signs of myoclonus that could indicate neurotoxicity

Rationale: Let Mrs. G know that when the morphine is initiated that Mr. G might sleep 8-10 hours after relief of his pain.

Family Education

- Keep a record of times and doses of medications administered
 - This will help if the need arises to increase medication
- Myoclonus (twitching) may occur at end-of-life due to liver and kidney failure
 - Morphine metabolites may not be processed effectively
 - Morphine greater than or equal to 1000 mg/day
 - Lorazepam is recommended to reduce myoclonus

Other Medications

Opioids are not the only medications to consider when treating a patient's end-of-life pain.

- Shooting radiating pain suggests nerve involvement – consider gabapentin or a tricyclic anti-depressant for this neuropathic pain
- Bone pain- consider titrating ibuprofen dose

When the patient can no longer swallow, there are a few options:

- Sublingual administration of immediate acting medication
- Rectal administration of extended release medication

Pain Management Myths and Facts

Myth: If you need morphine, it means death is near

Fact: Morphine is the drug of choice for end-of-life pain management; but its use does not signal impending death.

Myth: Pain medicine will make me sleep all the time

Fact: Our bodies adjust to the effect of sedation from pain medications within just a few days

Myth: If I take too much pain medicine, it will not work later when I really need it

Fact: Tolerance is a common occurrence in individuals when certain medications are taken continuously. If

tolerance to a certain dosage does occur, it can safely be increased, or a different drug can be used.

Myth: Pain medications interfere with breathing

Fact: When pain medications are used routinely during end-of-life care, the patient will develop a tolerance, not an addiction, to the opioid. This tolerance of the pain medication is also a tolerance of the side effects. Respiratory depression may not occur as readily because of this tolerance.

Constipation

Constipation is infrequent bowel movements or difficult passage of stools. Constipation interferes with quality of life. It occurs in nearly all patients receiving opioids. A host of unpleasant symptoms can accompany constipation:

- Increased pain
- Nausea and vomiting
- Anorexia
- Weight loss
- Bowel obstruction
- Urinary retention
- Fever
- Sepsis
- Erratic absorption of medications
- Ileus

Constipation: Causes

There are numerous causes of constipation and they can be classified as lifestyle-related, disease-related, or opioid-induced. Constipation can be caused by:

- Certain diseases
- Advancing age
- Decreased physical activity
- Low fiber diet, depression
- Cognitive impairment,
- Medications such as opioids, calcium channel blockers, diuretics, anticholinergic drugs, iron, serotonin antagonists, and chemotherapy
- Metabolic abnormalities, such as hypercalcemia and hypothyroidism.

Constipation: Management

Management of constipation usually starts with identifying and treating the underlying cause. If a reversible cause cannot be addressed, then symptomatic treatment should be initiated. If the patient has not had a bowel movement for three or more days, medications should be considered. Common medications that may be used to treat constipation include:

- Bulk laxatives – methylcellulose, polycarbophil, psyllium
- Stool softeners – docusate calcium, docusate sodium
- Osmotic laxatives – lactulose, magnesium citrate, magnesium hydroxide, polyethylene glycol, sodium bisphosphate, sorbitol
- Stimulant laxatives – bisacodyl, cascara sagrada, castor oil, Senna

- Prokinetic agents - tegaserod

When all else fails, manual decompaction may become necessary. Placing the patient on a bowel regimen may be useful.

Assessing Bowel Status

The significant parameters to assess include:

- Degree of distention
- Bowel sounds
- Color, volume, odor of vomitus
- Level of consciousness
- History and onset of concomitant symptoms

Family/patient education is important to bowel assessment. Ensuring that the caregiver can describe distention, for example, will help determine the type of care received.

Did You Know?

- Color, volume, and odor of vomitus can tell us whether it is bile or stomach contents or has become foul smelling and dark which might indicate bowel obstruction.
- Nausea and vomiting may slow bowel function
- Decrease in level of consciousness may decrease bowel function

Case Study

Mrs. T has stage 4 ovarian cancer with extensive abdominal metastasis and receiving hospice services. She is on MS-ER 300 mg Q12H with MSIR 50-100 mg PO Q1H PRN for breakthrough pain. She also takes 8 Senna tabs daily with 8 tabs docusate sodium. She has frequently required sorbitol and Fleets® enemas for relief of constipation. She now reports nausea and vomiting of dark, foul-smelling emesis, and increased abdominal distension.

Test Your Knowledge

What is the most important INITIAL action of the hospice nurse who visits?

- a. Insert a nasogastric tube
- b. Auscultate bowel sounds
- c. Check for fecal impaction
- d. Discuss the patient's goals**

Rationale: A hospice patient first talks to her about what may be happening. Many patients are aware of the changes that occur with a bowel obstruction. They may understand that they are vomiting stool and that this has implications. The most important thing is to explore with the patient her awareness of the meaning of some of these symptoms and what direction she wants to take.

Agitation and Delirium

Difference between agitation and delirium

- Agitation – excessive restlessness, increased mental and physical activity, inability to be consoled.

- Delirium – an acute alteration in mental status which includes:
 - Clouding of state of consciousness.
 - Development of symptoms over hours to days.
 - Fluctuation of signs and symptoms.
 - Normalization or improvement after treatment of underlying condition, or spontaneous recovery.

While commonly associated with the elderly patient, even younger patients, can experience an acute episode of delirium after spending time in the hospital.

Delirium: Causes

Many circumstances common at end of life can cause delirium, including (Nunn, 2010):

- Dehydration, metabolic changes
- Hypoxia
- Acute cerebrovascular accident, myocardial infarction, renal failure
- Infection
- Pain
- Environmental changes, such as removing, adding, or rearranging items
- Urinary retention
- Fecal impaction
- Medications /polypharmacy; particularly anticholinergics, benzodiazepines, opioids, steroids, digoxin
- Unfinished business, unresolved psychosocial issues

Delirium: Management

Pharmacologic Interventions

Haloperidol (Haldol®) is the medication of choice for managing delirium. It does not produce the paradoxical effects that benzodiazepines might cause. The dose depends upon the patient's weight and is usually ordered: Haloperidol 1-5mg PO/IM/IV Q1H until calm. Maximum x 6 doses/24H then Q4H.

For agitation, lorazepam may be given, only if the patient has no dementia and is not of advanced age. Benzodiazepines must be used with caution because of the potential for a paradoxical effect.

Delirium: Management

Non-pharmacologic Interventions

Because so many factors can contribute, it is important to assess and eliminate underlying and pharmacologic causes, such as:

- Anticholinergics, steroids, opioids, or benzodiazepines
- Overstimulation, constant television or barrage of visitors, lack of routine

Techniques which may help decrease delirium are:

- Familiar faces
- Routines
- Subdued lighting
- Pain management
- Complimentary Therapies
 - Pet therapy

- Music therapy
- Aroma therapy

Caring for the Dying Patient

As the patient approaches death, the goals of symptom management become even more profound. The goal is to achieve a peaceful death experience for the patient. Symptom management in this setting becomes more simplistic and should be viewed in the context of the whole person who is the patient.

Guiding principles for the last weeks:

- Patient choice and control
- Balance between activity & rest
- Titration to relief of symptoms
- Focus on patient goals

Symptom Management

Symptom management is very important to the quality of end-of-life care. Symptoms take on different meanings at end of life. Anxiety, fatigue, and emotional, psychological, and spiritual distress can exacerbate symptoms. When the patient experiences extreme pain or uncontrollable nausea, it's difficult to deal with anything else.

Caring for the Dying Patient: End of Life Needs

Maslow's theory on the hierarchy of needs can be used to view and frame the dying experience and focus interventions to provide the patient and family a peaceful death experience. Zalenski and Raspa (2006) modified Maslow's original hierarchy and adapted it to palliative care.

The five levels, from the bottom to the top, are:

5. Self-actualization needs – growth in illness, peace, and transcendence.
4. Esteem needs - value, respect, and appreciation for the person;
3. Love and Belonging needs - affection, love and acceptance in the face of devastating illness;
2. Safety needs - fears for physical safety, of dying or abandonment;
1. Physiological needs - distressing symptoms, such as pain or dyspnea;

When the bottom level is not met, those basic needs of comfort, the patient can't do the important work of dying.

The Work of Dying

Only approximately 6% of deaths are sudden deaths. Most people know in advance what disease process will take their lives. It is important that the patient resolves the following issues; however, not everyone will need to work through each process.

- Resolving Life Issues
 - Have I done everything I was supposed to do?
 - How do I fix those things that need fixing or finishing?
- Practical and Emotional Planning for the Well-Being of Loved Ones Left Behind
 - What should I do with the house?
 - Should I clean up the garage so that my wife doesn't have to deal with it when I'm gone?

- Family members and caregivers may not be ready for this planning as early as the patient is. Palliative care professionals can help by listening to the planning process and act to bridge those conversations.
- Finding Meaning
 - Finding meaning in life, suffering, and dying
- Coping with Fears of Loneliness and/or Abandonment
 - Family members also experience feelings of loneliness and abandonment as they contemplate the death of their loved one
 - Patient and family become the unit of care as they walk through the process together
- Acknowledging One's Individualized Meaning of Departure from This Life
 - In her model of death and dying, Elizabeth Kubler-Ross identified "acceptance" as the final stage in the process. However, at the end of her own life, she expressed a different belief. She saw not a nice, neat process, but rather the reality that not everybody goes through some of the stages she had identified - it can be a very erratic process.

Acceptance implies that everything's just fine, which is rarely the case. However, many people can really get to a place of acknowledgement and say, "I'm dying and that's okay."

The Work of Dying: Spiritual Issues

Never think that those who lack a formal religious background or faith practice have no spiritual issues that they're working through. All of us, regardless of our belief systems, will begin to examine what we really believe. This is a time of introspection and reconciliation.

- Examining beliefs relating to death, eternal life, and afterlife
 - People of faith may struggle with, "I've believed this all my life, is it true? Am I being strong enough?" Many people of faith struggle with a fear of dying because they feel that they should be stronger than that and they are hard on themselves.
- Reconciling with God or others
 - Atheists too, who may not believe in an afterlife or Supreme Being, still struggle with existential issues, "Why was I here? What did I live for? Do I need to be reconciled with other people?"
- Determining the meaning of pain, suffering, dying process

Tailoring Symptom Management to Patient Goals

As death approaches, patients begin to sense their own decline. They know their bodies and their body clocks very well, even if they don't know their disease processes. This can be a difficult time for family as the patient begins to lose interest in socialization. The patient is conserving energy at the very same time that the family may want to hold onto that person just a little bit longer.

During this time, empower patients and families by giving the patients choice and control over what they eat and do, finding the right balance between activity and rest, symptom relief, and determining goals.

The most important thing may be, "I want to go ride my horse one more time." Manage symptoms so the patient can reach that goal.

Care of the Dying

Several weeks preceding death, the body begins to shut down. Most patients are becoming close to bed-

bound, if not already bed-bound. The patient typically exhibits:

- Obvious physical deterioration
 - Potential for increase in symptoms
 - Some cancer patients might exhibit a spike in pain about 6-8 weeks before death as the metastasis or disease makes that final push into the system. Usually, once pain is controlled, it stabilizes.
 - Difficulty swallowing, disinterest in food.
 - It feels like something's stuck in my throat
 - The body is saying, I don't need many calories anymore and the gut slows. The body naturally knows not to eat
 - Decreasing mobility, loss of independence
 - Increased likelihood of incontinence
 - Changes in sleep/rest patterns
 - The patient may sleep 18-22 hours a day
- (Dans & Sheldahl, 2015)

Emotional withdrawal. Patients try to conserve their energy for simply breathing or having a conversation or two in a day. The withdrawal is difficult for the families who begin to sense, "I'm losing my loved one."

The Weeks Before Death: Comfort Measures

- Manage dysphagia
 - A small dropper or oral syringe may be useful to administer liquids, just to moisten the oral cavity
- Manage incontinence
 - Use of incontinence products instead of an indwelling catheter
 - Protect skin from breakdown if possible
- Manage changes in sleep patterns
 - Maintain a calm environment
- Manage symptoms
 - Now is not the time to worry about addiction issues
- Support the Family
 - Help them cope with the patient's emotional withdrawal
 - Help them cope with feelings of guilt if present

Days and Hours before Death

In the last days of life, it becomes very evident to the family that time is running short. The goal is to keep the patient comfortable.

- Symptom management is very important
 - Symptoms should be managed with a minimum amount of invasiveness
 - Preserve the patient's dignity and mental clarity
- Educate caregivers to their level of need
 - Some may ask many questions
 - Some may not want to know
- Allow caregivers to participate in care
 - Helps combat the feeling of helplessness

Comfort Measures in the Last Hours

In the hours before death, the comfort measures for the care of the patient become relatively simple. Sometimes the care of the family becomes a little more intense in the last day or hours of death as they understand the significance of what they are seeing.

Although most deaths are peaceful with hospice care; breathing stops, the heart stops, and the patient appears to be peaceful, this is not always the case. Let the family know what to expect, both good and bad; remove the fear of the unknown.

- Labored respirations are common and often the most distressing for family members
 - Airway congestion leads to noisier respirations
 - Medication does not always alleviate these symptoms
 - Repositioning may help

While no one can truly define what a good death is, knowing and achieving the patient's goals is what end-of-life care is about!

Tasks of Grieving

Grieving the loss of a loved one is a part of life everyone goes through at some point in their life. It is important for the family to know that not all people grieve in the same manner and that each person should be supported through this time

Conclusion

End-of-life care can be as rewarding as it is sad. Knowing how to meet your needs as well as those of the family and patient can make the difference between a "good" death and a not so good death.

Resources

American Academy of Hospice & Palliative Medicine <http://www.aahpm.org>
Center to Advance Palliative Care <http://www.capc.org>
Hospice & Palliative Nurses Association <http://www.hpna.org>
Arizona Hospice & Palliative Care Organization <http://www.ahpco.org>
National Hospice & Palliative Care Organization <http://www.nhpco.org>
National Council for Palliative Care <http://www.ncpc.org.uk/>
Worldwide Hospice Palliative Care Alliance <http://www.thewhpca.org/>

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There is "off label" usage of medications discussed in this course.

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Note: All dosages given are for adults unless otherwise stated. The information on medications contained in this course is not meant to be prescriptive or all-encompassing. You are encouraged to consult with physicians and pharmacists about all medication issues for your patients.