End of Life / Hospice Care

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Objectives

By the end of this educational experience, the nurse will be able to:

Identify normal physiologic processes related to end of life care.

Recognize comfort treatments related to end of life care

Recall nursing interventions for the patient and family in end of life care.

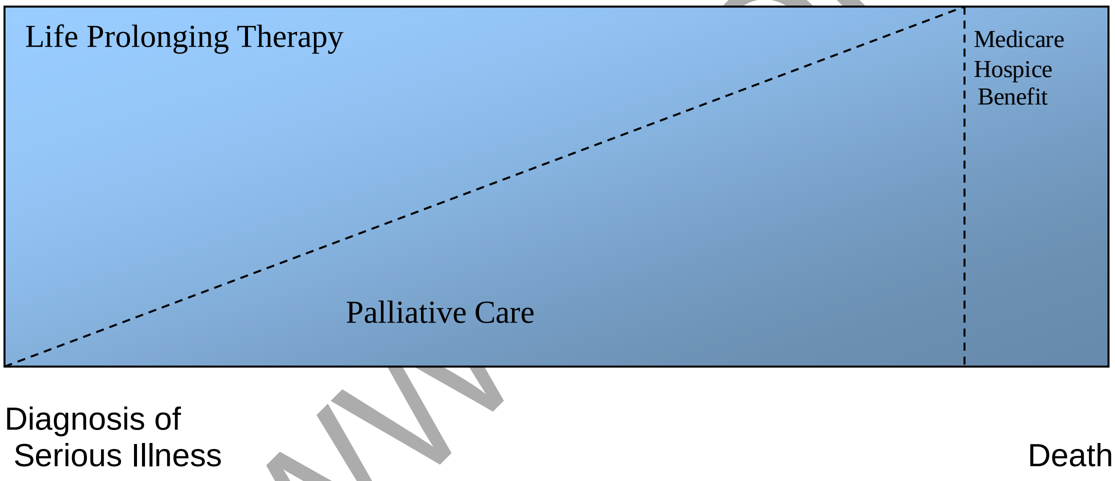
Introduction

In this continuing education activity, nurses will receive knowledge about current issues in end of life care, emotional issues of the care provider, patient, and family that can affect end of life care, and nursing interventions in the physical, emotion, and spiritual realms for the patient and family.

End of life care is associated with many terms, hospice care, palliative care, terminal care, and death and dying. However, these terms may cause the practitioner to focus on the negative aspects of this area of nursing and not the true focus of palliation which is to achieve the highest level of quality life possible for the patient in the time that they have remaining. This shift in thinking alone can transform death from a concept of protracted decline into an event that occupies a small space in time, providing a healthier atmosphere for care providers, patient, and family.

The field of hospice care provides the theoretical and historical framework for palliative care, so it is appropriate to provide a little history on the hospice movement. The concept of hospice was founded in 1967 by Dame Cicely Saunders, a nurse who later became a physician. Her goal was to bring a dignified and respectful death back into the home in a painless environment accented with family and friends. Hospice philosophy looks upon death as a natural part of the life cycle, and supports a holistic approach to the individual with emphasis on not only the physical needs of the patient, but also the spiritual, social, and psychological needs of the patient and the family.

The definition of palliative care developed by American Academy of Hospice and Palliative Medicine (AAHPM) explains the concept of palliative care "The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care"(National Consensus Project).



Treatment of Pain

Pain is considered the fifth vital sign and should be assessed as frequently as all the other vital signs. In fact, failure to treat or under managing pain can place the clinician at risk of legal liability.

It its important to note that there are different types of pain and each one has different characteristics and thus a slightly different approach to treatment. Somatic pain is well-localized pain that is frequently described as an ache, throb, sharp, or pressure. This type of pain most often arises from bone or soft tissue. Visceral pain characteristics usually include diffuse pain that is squeezing, cramping, or gnawing. Burning, tingling, shooting, or shock like pain is usually neuropathic in nature and is often the result of a lesion affecting the central nervous system (Fine, 2007).

The nurse should assess the severity, type, quality, and character of the pain and document the findings in the patient's medical record. This information and ongoing assessment is vital to adequately controlling pain. Medications that are administered should be documented according to time of administration, dosage, route, and patient response. Also documenting the duration of pain relief is a vital clue in helping the medical team adequately manage the patient's pain.

Step 1 treatment is used for mild pain that is rated on a scale of 1-3. Step 2 treatment is for moderate pain on a scale of 4-6 and may be used in addition to step 1 agents. Step 3 treatment is reserved for severe pain with a pain rating of 7 or above on the pain scale, or pain that persists after step 2 treatment. Step 1 drugs and adjunctive therapies such as heat, cold or massage can be used at any step in the process. In order to be effective analgesics need to be administered on a round the clock basis, patients need to be encouraged to alert nursing staff to any pain that they are experiencing, and not to try to 'tough it out' (Fine, 2007).

MANAGEMENT OF PAIN ACCORDING TO THE WORLD HEALTH ORGANIZATION (WHO) LADDER

Drug Typical Starting Onset of Action Duration of Action
Dose and Route* (Hr)
WHO Step 1: Mild pain

Starting Dose & Route	**Onset of Action**	**Duration/ hr**
Aspirin 650 mg PO	30 min	3-4
Acetaminophen (Tylenol) 650 mg PO Maximum 4,000 mg per day	15-30 min	3-4
NSAIDs Ibuprofen (Motrin) 200-800 mg PO	30 min	4-6
Naproxen (Naprosyn) 250-275 mg PO	60 min	6-12
Indomethacin (Indocin) 25-75 mg PO	30 min to several hrs	4-12

Step 2: Moderate pain

Starting Dose & Route	**Onset of Action**	**Duration of Action/hr**
Acetaminophen combinations: Plus codeine (Tylenol #3	30 min	3-4

or #4) 60 mg PO		
Plus oxycodone (Percocet) 5-10 mg PO	Varies	3-4
Plus hydrocodone (Vicodin, Lorcet) 10 mg PO	30-60 min	4-6
Codeine 30-60 mg PO, 30 mg IV/SQ	30-45 min	4-6
Hydrocodone 10-30 mg PO	30-60 min	4-8
Morphine** (immediate release) 15-30 mg PO 1-10 mg/hr IV 4-15 mg SQ	30 min 10-30 min 10-15 min	3-4 3-4 **3-4**

Step 3: Severe pain

Starting Dose & Route	**Onset of Action**	**Duration of Action/ hr**
Morphine (sustained release) 15-30 mg PO	60 min	8-12
Oxycodone (immediate release) 10 mg PO (Roxicodone)	10-15 min	3-6
Oxycodone (sustained release) 10-20 mg PO (OxyContin)	30 min	12
Hydromorphone (Dilaudid) 4-8 mg PO 1-2 mg IV	15-30 min	12 2-4
Methadone 5-10 mg PO 2.5 mg IV	30-60 min	4-8
Levorphanol (Levo-Dromoran) 2-4 mg PO	10-60 min	6-8
Fentanyl (Duragesic, Sublimaze) 25 mcg PO 5-10 min Transdermal patch (25 mcg/hr)	**5-10 min** 12-24 hr	Varies 48-72

Rescue doses of medication should be available for the patient’s use for times when pain appears before the next dose of maintenance medication may be given. The rescue dose should be 5 to 15 % of the total 24-hour maintenance dose, with oral doses being repeated every hour until pain is controlled. If the patient requires more than three rescue doses of a medication in a 24-hour period, then the maintenance dose should be increase by 25 to 100% (Alexander, 2006).

To be most effective, pain medications should be given on a round the clock dosing schedule (Alexander). Patients need to be encouraged to take their medications in this manner to keep a steady amount of medication in their system and to prevent needless episodes of pain. Pain medications are less effective when the patient waits until the pain gets intense to take their medication.

Non-steroidal antinflammatory medications (NSAIDs) are most useful for patients who have bone pain. NSAIDs are available OTC as well as by prescription. The patient may need to be tried on different medications to find the one that is most effective form them. One drawback to these medications is that they have a therapeutic ceiling, or a dose limit beyond which no higher dose of the medication will prove beneficial. Side effects of these medications can be decreased platelet adhesion and GI bleeding (Alexander).

The opioid class of pain medications has no ceiling and can be titrated upwards until pain relief is obtained. For patients who are naive to opiates immediate release morphine is the starting drug of choice. For patients who are unable to swallow, the transdermal route is a viable option; however, fentanyl does not take effect for at least 12 hours after application so another analgesic must be provided in the interim.

Side effects of opiates are many and the most notable is constipation, which has an occurrence rate of nearly100%. The nurse should educate patients and caregivers about this side effect. Constipation can be managed by the routine administration of stool softeners. Other common side effects such as nausea and sedation will subside within 3 to 7 days as the patient begins to tolerate the medication. It is important for the nurse to educate the patient and family that these are not allergic reactions to the medications and that true allergies to opiates are not common occurrences.

Another important aspect of nursing education for patients and families is that high doses of opiates will hasten death. The patient and family need to be instructed that this idea is false and is unsubstantiated by medical fact. In fact, the exact opposite is true, unrelieved pain causes stress that can hasten death (Fine, 2007). This stress leads to decreased mobility, decreased immune function, and increases in cardiac demands, oxygen demand, increased risk of pneumonia and blood clots. The untreated pain can lead to spiritual and psychological stress that can compound the previously mentioned risk factors, exponentially increasing the likelihood of an earlier death, and certainly one with a markedly diminished quality of life.

Adjunctive medications can also be used to enhance the properties of primary pain medications. These therapies include antidepressants, anticonvulsants, corticosteroids, local anesthetics, radiation, and surgical treatments.

Antidepressants are number one in five for first line drugs in the treatment of neuropathic pain. The tricyclics are usually the most commonly used, however, they can have prohibitive side effects. For patients who cannot take tricyclics, the SNRI's, such as Effexor and Cymbalta may bring substantial adjunctive pain relief, minus the side effects of the tricyclics (Fine, 2007).

The anticonvulsant medications carbamazepine and clonazepam relieve pain by blocking the sodium channels of nerve cells. Gabapentin is thought to block pain impulses by affecting the calcium channel of the nerve cell (Fine, 2007). When the movement of sodium or calcium ions into and out of the cell is regulated by medications, the action potential of the cell is altered. This is the reason that anticonvulsants are effective at controlling neuropathic pain.

The usual starting dose is 100mg three times per day. The most usual reason for failure to achieve pain control with this medication is not titrating the dose upward. For non-palliative care, doses of 900 to 3,600mg per day, in divided doses, have been used. If Gabapentin is discontinued, it needs to be tapered gradually to prevent seizures (Fine, 2007).

Corticosteroids are useful adjunctives for bone pain, visceral pain, and bone pain. They are especially useful in patients who have stretching of the liver capsule due to metastatic disease. Dexamethasone is the least toxic of all the choices and comes in a wide range of administration forms. The dose is usually 16 to 24 mg per day and can be given in one dose or divided to decrease potential side effects such as blood sugar spikes and psychosis. Dosages of up to 100mg may be used (Fine, 2007).

Treatment of Respiratory Symptoms

Breathlessness is a symptom that can be distressing to both the patient and their family members. Dyspnea can occur because of anxiety, or anxiety can be a result of dyspnea, leading to a viscous cycle of worsening symptoms. It is therefore important that the clinician carefully assess reports of dyspnea to discover if they are related to physical or psychological processes and treat accordingly.

Treatment for dyspnea can include supplemental oxygen, non-pharmacological interventions, opiates, and other medications. However; these intervention may not alleviate the dyspnea, depending on the cause of the symptoms.

The use of oxygen may be most beneficial in patients with COPD or terminal heart disease. Non-pharmacological approaches may actually be more effective when used in conjunction with oxygen. A fan blowing cool air into the patients face has found to be more effective than a 100% non-rebreather mask in relieving dyspnea (Alexander, 2006).

Elevating the head of the bed or repositioning the patient can often ease the work of breathing, and assisting the patient with pursed lip breathing exercises can offer the patient a measure of control over the rate and depth of respirations as well as provide a distractive element. Creating a calm environment, free from stimulating factors may also be beneficial for the patient who is dyspneic. Other measures to improve breathlessness include:

- Position the patient so that he or she can see outside
- Open the windows if at all possible
- Limit the number of persons in the patient's room
- Minimize the amount of healthcare equipment and noise
- Eliminate noxious odors. (cooking, smoking, pet smells, cleaning solution and perfumes)
- Try to maintain sufficient humidity in the room
- Play soothing quiet music
- Try to keep the room temperature comfortable for the patient. Cooler air is easier to breathe

Medications that are successful in treating dyspnea include anxiolytics such as the benzodiazepines. These can alleviate dyspnea that is related to stress and help the patient to relax. These medications should be started at low doses and titrated to the desired effect. Benzodiazepines can safely be used with opiates (Alexander, 2006). If the patient is fluid overloaded from CHF, diuretics may be beneficial and provide relief. For patients with COPD, bronchodilators may provide relief.

Opioids can help with breathlessness by decreasing the work of breathing, reducing oxygen demand, and decreasing the patient perception of dyspnea. Respiratory depression with doses of opioids necessary to decrease dyspnea has not been shown to be a problem in clinical use (Alexander, 2006).

Treatment of the buildup of respiratory secretions can help to ease breathing and lessen the distress of the family that noisy respirations can cause. It is most helpful to initiate these medications before the secretion pool becomes large, as then it will be more difficult to eliminate. The starting doses of these medications are:

Scopolamine 0.2-0.4mg sq every 4 hours or patches placed behind the ear 1-3 patches ever 72 hours. For continuous IV 0.1-1.0 mg/hr.

Glycopyrrolate 0.2mg Sq every 4-6 hr, or0.4-1.2 mg/hr by continuous infusion (Emanuel, 2006)

Use of these medications while the patient is still alert may cause unacceptable drying of the mouth and throat, which the patient may find uncomfortable. Once the patient is unable to swallow, all attempts at oral feedings and fluids should be stopped. Small amounts of medications may be given via the buccal mucosa if necessary. Suctioning of the pharynx and mouth is not recommended. Secretions are usually beyond the reach of a suction catheter, and the procedure may cause unnecessary stimulation of the patient and distress for the family (Emanuel, 2006).

Treating Gastrointestinal Symptoms

One of the most common causes of gastrointestinal symptoms in end of life care is constipation, which was mentioned briefly under pain management. Patients may be reluctant to inform their healthcare practitioner of the symptoms of constipation, so the nurse should take a proactive approach in informing the patient and family about what to expect, especially if the patient is taking narcotic pain medications.

If the use of stool softening medications is ineffective, then Senna (Senekot) 1-2 tablets orally once or twice daily or Dulcolax 2 tablets at bedtime may be used. These medications may be titrated upward to produce 1 soft bowel movement every 1-2 days. Other interventions may also be used such as increased fluids; fiber supplementation, preferably by diet as tolerated by the patient, may also be used. Physical activity, as the patient’s condition permits, is essential for promoting intestinal motility.

One symptom that is distressing to family members is the loss of appetite and resultant weight loss of the patient. Our culture closely equates food and fluid intake with health and the family may feel that the patient is starving to death. However, studies have shown that increased food intake near the end of life odes not always result in weight gain, nor does either one lead to increased survival (Alexander, 2006)

The patient should have a complete assessment to look for causes of appetite loss and wasting other than the disease process. Treatment is directed at the cause of the symptoms. If the cause is related to disease process, then non-pharmacological approaches are best such as serving small frequent meals, placing healthful snack within easy reach of the patient, such as raisins, dried or fresh fruit, ect. Foods that appeal to the patient are usually best. If the patient is not wanting hot foods, try cold ones or vice versa. High calorie nutritional supplements that the patient can drink are also beneficial.

Treatment of Fatigue and Weakness

Fatigue is one of the most common symptoms that is experienced near the end of life. This may be due to increased metabolic processes of metastatic disease, depression, pain, or the side effects of medications, especially narcotics.

Adequate pain control is one of the most important interventions in controlling fatigue. Other measures include energy conservation and the use of assistive devices for activities of daily living. The patient should save taxing activities for the time of day when he or she is most rested, and should be encouraged to rest in between activities.

If fatigue is caused by an underlying pathology such as depression or anemia, then pharmacological management to these processes is certainly appropriate to give the patient an increased quality of life. Corticosteroids can be considered for a one-week trial to determine if the fatigue is alleviated, however, the effect may dissipate after 4-6 weeks (Alexander, 2006).

Treatment of Delirium

Delirium is an alteration is consciousness that may be exhibited as three different types: the hypoactive subtype is manifested by decreased motor response and very little speech (approximately 50% of patients), the hyperactive type exhibits agitation and hyperactive motor behavior (approximately 25%), the third type is a mixed type and patients exhibit a combination of both types (approx. 25% of patients) (Alexander, 2006).

Delirium can be extremely stressful for both the patient and the family with over half of patients reporting that they can recall episodes of delirium. Terminal delirium is a distinct entity and occurs in 88% of patients with the last hours of life. Unrelieved pain has been found to be a large factor in terminal delirium; however, other factors can also be involved such as infection, medication effects, hypoxia, and others.

If a reversible cause for delirium cannot be found and the patient is agitated, Haldol is the drug of choice. Melleril, ativan, and Versed may also be used.

However, benzodiazepines can actually worsen agitation and should only be considered when Haldol does not work.

Psychological, Social, and Spiritual Treatment

A holistic approach should be the central theme to the end of life process. A multi-disciplinary team approach is most effective, with the patient having access to social work or counseling services, clergy or pastoral services, and psychiatric care if necessary.
These services should be extended to the family as well. Caregivers frequently experience fatigue, burnout and overwhelming frustration as their loved one nears the end of life.

Care of the Patient and Family at Imminent Death

As it becomes evident that the patient's death is becoming imminent, it is important for the clinician to prepare the family for the process of death. Explaining to the family what may happen will lessen their discomfort with the dying process. Explaining to the family and caregivers that as fatigue worsens and the patient looses consciousness, loss of bladder and bowel control may occur due to lose of sphincter tone. This will make frequent skin cleansing and care more important to prevent skin breakdown and patient discomfort.

The family should be informed about changes in respiration and skin that occur in the patient's last hours as well as the possibility of delirium and seizures. Seizures should be treated with benzodiazepines or antiepileptics until control is achieved. The family should also be educated that if pain control has been adequate throughout the patient's illness, it is unlikely that pain will escalate in the final hours.

When the patient stops eating and drinking, it is important to inform the family that this is not distressing to the patient and may actually lead to a patient's sense of well being through the release of endorphins. Inform the family that attempts to feed the patient may lead to discomfort and the possibility of aspiration.

It may be helpful to the family to participate in the patient's care by being shown how to perform mouth and lip care to increase the patient's comfort and dignity. Conjunctival care should be performed as well if the patient has no blink reflex.

The family should be encouraged to spend time with their loved one in a quiet and calm environment. Encourage the family members to talk to the patient as if he or she can hear them. It is not certain how much an unconscious person can hear and remember, but patients that were thought to be unconscious have reported that they were able to hear and remember conversations going on around them. They should be encouraged to stroke, or touch the loved one just as they always have.

When death of the patient does occur, allow the family adequate time with the body of their loved one. The nurse should ask for a few moments of privacy with the patient to prepare the patient. If it is clear that autopsy is not indicated, remove all catheters, lines, and tubes unless mandated by state codes. Perform any necessary clean up of blood or body fluids and arrange the body in a comfortable relaxed position. Allow the family adequate time before the funeral home is called to remove the body. The family should also be offered services from counselors, social workers, or clergy as appropriate.

Conclusion

Care of dying patients is a subject that clinicians are often uncomfortable and unfamiliar with. Open communications between, caregivers, patients and families is an essential element of end of life care. The clinician can enhance his or her comfort level with death and dying through education on the physiology and management of the death and dying process.

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