

Module Four

Competency 4 End of Life Planning / Dying and Death Management

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Competency Four

End of Life Planning / Dying and Death Management

Objectives:

- 1. Demonstrate knowledge of pain and symptom management strategies unique to the last hours of life.**
- 2. Anticipate, recognize and responds to signs and symptoms of imminent death.**
- 3. Create a physical, cognitive and emotional environment around the dying person allowing his/her caregivers to be with him/her throughout the terminal illness.**
- 4. Implement end-of-life care with minimal use of machines unless specifically desired by the dying person or unless palliation of symptoms is not possible without use of such technologies.**

Definitions

Cheyne-stokes Breathing	Rythmic waxing and waning of respiratory depth with regularly recurring apnea, seen in coma.
Death rattle	A rattling or gurgling in the throat of a dying person.
Kussmaul respirations	Air hunger, distressing dyspnea occurring in paroxysms (sudden recurrence or intensification of symptom)
Mottling	discolored areas, usually of the skin
Signs of death	Cessation of heart beat and respiration, pupils fixed and dilated. No response to stimuli, eyelids open without blinking, decrease body temperature, jaw relaxed and slightly open, body color is a waxen pallor.

Myths

1. Pain medication causes confusion in most people.
2. Death rattle is a sign of severe dyspnea.

Signs and Symptoms of Approaching Death

The dying process is variable depending on individual and family characteristics but there predictable physical, physiologic and emotional changes that occur during the final days and hours of life. Symptoms that have been a problem previously often cause difficulties and may increase in severity in the last weeks of life. (Kemp, 1999). However, there is seldom a “crescendo of pain” in the final days, there is often an

increase in pain or other symptoms (especially dyspnea) (Twycross & Lichter, 1998). The nurse helps the family prepare for the approaching death. Knowing what to expect is vital for the nurse to meet patient and family needs before, at and after the death.

Causes of death: The three leading causes of death in adult Americans continues to be cardiovascular disease, cerebrovascular disease and cancer. Irreversible failure of body systems leads to death but the cause of death is always cardiopulmonary failure. Death occurs when the heart or the lungs fail to perfuse and oxygenate vital tissues. Circulatory failure or pulmonary failure precedes death. Table 1 lists the best indicators of imminent death, which are the signs and symptoms of cardiovascular and respiratory failure.

Table 1. Signs and Symptoms of Imminent Death

System	Etiology of Failure	Signs	Symptoms
Circulatory	Myocardial infarction, arrhythmias, blood loss	Reduced tissue perfusion (decreasing blood pressure, tachycardia, irregular pulse, reduced mentation, cooling and cyanosis of the extremities	Chest pain, dyspnea
Pulmonary	Pneumonia, Thromboembolism, Pleural effusion, Pulmonary edema, pulmonary or tracheal obstruction, depression of medullary respiratory centers	Hypoxia with hypercapnia (slowed mentation, confusion, restlessness, coma, orthopnea, irregular or rapid breathing, tachycardia, use of accessory muscles to breathe excessive secretions	Apprehension Dyspnea, cough, fear of choking or drowning

Physical, physiological, and emotional - In the final days and hours before death, a number of signs and symptoms occur in a predictable pattern. Changes in daily habits and bodily functions and decline in functional status are observable and often distressing to the patient and family. Anticipating the changes and symptoms and preparing the patient and family to expect and deal with them decrease the uncertainty that often plagues this time of life.

Table 2. Develop a Careplan for End-of-Life Care

Weakness & Fatigue	Dyspnea
Secretions	Respiratory Changes
Pain	Delirium
Dry membranes	Agitation
Skin Care	Incontinence

Dreams and Visions – Dreams and visions tend to increase in frequency in terminal patients during their final weeks and days. These are usually comforting to the person that is dying (Kemp, 1999). Powerful themes and symbols appear in these dreams and visions.

Withdrawal – Many patients will withdraw, not in despair, but in acceptance of death. You may notice that these patients speak very little to loved ones or to their favorite caregivers (Kemp, 1999). This is a natural part of the dying process, and it is important to inform family that this is not a depression or rejection of others (Kemp, 1999). Once family members understand this process, it is usually accepted.

Eating – A few people continue their dietary habits until they die. The typical dying person, however, stops eating all but a few bites of favorite foods. “Stopping eating is a predictable sign that life is drawing to a close; dying requires not nutrition” (Blues & Zerwekh, 1984, p. 180.). Family members often attempt to force the person to eat, creating conflict and turmoil. An important role for the nurse is to help the family recognize that the disease results in swallowing difficulties, food digestion problems or lack of energy or desire to eat. Instead of focusing feeding the dying person, the family can focus on providing comfort – give ice chips, frequent sips of fluids, cleanse the mouth and moisten lips. These comfort care actions can replace the giving of food when the dying person refuses or is unable to eat.

Drinking and hydration - They typical dying person also stops drinking all but a few sips of water or a favorite beverage. Thirst is not usually a problem, but a dry mouth is extremely uncomfortable. Comfort care usually is effective in relieving the discomfort of not drinking. Intravenous or subcutaneous hydration is possible but unnecessary and often leads to unpleasant complications. When families desire everything that can be done regardless of the potential for increased symptoms, limiting the hydration to one liter per day is preferable to the typical three liters per day given acute dehydration situations.

Oliguria - Renal failure is a common sign of impending death. Low urinary output of less than 30 cc/day or concentrated urine is a sign of renal shutdown. Incontinence may also occur. A foley catheter can be a great source of comfort for both the patient and family exhausted from frequent bed changes necessitated by incontinence.

Difficulty breathing – Breathing patterns change as death approaches. Dyspnea, productive cough and rattling breathing are examples of changes in breathing that predict the last days of life. Many strategies are helpful in relieving those respiratory symptoms and the death rattle.

Cooling and cyanosis of extremities – Circulatory collapse is indicated by cooling of the extremities and subsequently by cyanosis. The usual pattern is for the feet to be cold and to have a purple-blue mottled appearance. The cooling and discoloration spreads up the legs and the hands become cold and cyanotic.

Decreased consciousness – Alertness is difficult to maintain as body systems function at less than optimal. The balance of oxygen and carbon dioxide, both of which are alerted with cardiopulmonary compromise, affects the level of consciousness. Sleepiness, indifference and possible disorientation lead to decreased level of consciousness. The dying person may respond to pain or aggressive stimulation but not talk or control body functions such as bowel and bladder control. Many people believe that a comatose person can hear but are not able to respond. Intriguing end-of-life experiences have led experts to suggest that we “speak to a dying person as if each of your words can be heard. Choose your words with care” (Blues & Zerwekh, 1984, p. 184).

Other signs – Disorientation, restlessness and changes in vital signs are other indicators of impending death. The probable cause of disorientation is similar to decreased consciousness. Reorientation and a calm presence are useful strategies to cope with this sign. Restlessness may be an indication of pain or discomfort. Careful assessment of potential sources of discomfort is important to appropriate management of the cause of the restlessness. Patterns in vital signs that reflect the imminent death are as follows:

- Subnormal temperature;
- Decreased then increased irregular and then absent pulse rate;
- Decreased then absent blood pressure; and
- Increased, irregular and then decreased with apnea respiratory rates.

The last days and hours can be the most significant time of our lives providing last opportunities to:

- finish our business
- create final memories
- give final gifts
- achieve spiritual peace
- say good-bye

In the last days and hours before death, the nurse learns to predict imminent death based on assessments that include astute observations of the patient’s physical conditions as well as the behavioral and emotional responses. Table 3 summarizes the common signs of approaching death. Table 4 summarizes uncommon but distressing events prior to death.

Table 3. Signs of Approaching Death: The last 48 hours

<p>Reduced level of consciousness</p> <p>Taking no fluids or only sips</p> <p>No urine output or small amount of very dark urine (anuria or oliguria)</p> <p>Progressing coldness and purple discoloration in legs and arms</p> <p>Laborious breathing; periods of no breath (Cheyne-Stokes breathing)</p> <p>Bubbling sound in throat and chest (death rattle)</p>

Table 4. Uncommon Uncontrollable Events Prior to Death

<ul style="list-style-type: none"> ➤ Uncontrollable pain when the pain was well controlled prior to death ➤ Fatal hemorrhage ➤ Seizure

Table 5. Signs of Death

<ul style="list-style-type: none"> ➤ Cessation of heart beat and respiration ➤ Pupils fixed and dilated ➤ No response to stimuli ➤ Eyelids open without blinking ➤ Decreasing body temperature ➤ Jaw relaxed and slightly open ➤ Body color is waxen pallor

Table 6. Basic Medications in the Final Day(s)

SYMPTOM	MEDICATION
Pain	Opioid
Dyspnea	Opioid
Secretions	Scopolamine
Restlessness / Confusion	Haloperidol + Midazolam Or Lorazepam Methotrimeprazine

Remember: Opioids should never be give as sedatives. They often increase agitation and delirium.

Teaching the Family – Final Points (adapted from Kemp, 1999)

- Depending on room temperature, a light blanket or sheet should be used
- Lighting should be whatever the patient has been using
- Conversation should not be hushed
- Children should not be kept out
- Nurse should reassure the family about the normalcy of events and help them to continue to provide as much care as possible.
- The importance of family is highly stressed. Everything that happens in the last hours of life will be remembered by the family. There will be grief, but there will also be the knowledge that the person who died was not alone in the final hours.

- Last Hours Checklist: Education
 - Previous experiences
 - Fears & Expectations
 - Changes with dying
 - Food & Fluid
 - Pain
 - Being with your loved one
 - Children
 - No 911
 - Pronouncement process

Absolute Necessities in the Last Hours

- Family & care provider education
- Multidisciplinary teams with 24-hour rapid response capability
- Adequate pain and symptom control
- A written care plan
- Institutional backup if patient is at home
- Enough help to avoid family exhaustion

After Death

Whether at home or in the hospital, there is a tendency to “hurry through” after the person dies (Kemp, 1999). It should be understood by all that there is not reason to hurry. Slowing the after-death events allows the family more time to begin to understand the reality of what has just happened and say goodbye (Kemp, 1999). Some families may wish to sit with the body, while others wish not to. Whatever the situation, the only reason not to encourage families to take as much time is related to public health rules, and these rules usually apply to a patient that has been dead for longer than 24 hours.

Those who provide end of life care only have one chance to do it right, if done well there is significant personal and family growth, if done poorly life closure can be incomplete, suffering may occur and bereavement may be difficult and prolonged. (Ian Anderson, 2000).

Case Study (adapted from: Ian Anderson Program)

Julian Smithers is a 68-year old man with non-small cell lung cancer diagnosed 9 months ago. He presented with increased dyspnea and substernal chest pain. He saw his family physician. An x-ray showed a large left hilar mass. Bronchoscopy and biopsy showed non-small cell lung cancer. He had radiotherapy to the mass. He was relatively well for two months when he developed thoracic back pain radiating around both sides of his chest. A bone scan showed metastases to T5, 6 and 7. An MRI showed a mass compressing the spinal cord. He received further radiation and morphine for pain control. He is now on 260 mg of sustained release morphine every 12 hours with reasonable pain control. He takes immediate release morphine 50 mg as breakthrough two or three times a day. Other symptoms include anorexia and cachexia (with weight loss of 15 kg), generalized weakness and mild dyspnea.

His past history includes mild hypertension treated with an ACE inhibitor and mild hypercholesterolemia treated with lovastatin. He is a non-smoker now but smoked heavily until 10 years ago. He drank small amounts of alcohol, mainly beer.

Julian was born in England and immigrated here 42 years ago. He lives with his wife Linda in a 2-bedroom condominium. They have been married for 37 years. They have 4 married children. John is the eldest son and he lives in Calgary, Alberta. His son Chris and daughters Jane and Barbara live nearby. Julian has 6 grandchildren, ages 6 to 13, whom he adores. He has a brother and sister living near London, England.

Julian worked for a small manufacturing firm and retired at age 65 on a company pension. He occupied his retirement with hobbies of gardening and photography. Linda who is 60, took early retirement from her civil service job when Julian developed cancer. This patient is on the palliative care program and you are the visiting palliative care nurse. You visit twice a week. The palliative care physician saw him once when he was admitted for the spinal cord compression. Julian is a Christian (protestant). He has been a regular churchgoer since his retirement. Linda is a Catholic but attends church with Julian. Julian has no written advance directive but has an established DNR.

Linda and Julian have discussed the illness with you on multiple visits. He has indicated that he would like to die at home. On your latest visit you find Julian lying in bed. He is drowsy but can be woken up. He speaks little but says he is not in pain. His oral membranes are quite dry and his tissue turgor is poor. His blood pressure is 84/56 and he has a regular tachycardia of 132/min. His respiratory rate is 18/minute with occasional brief periods of apnea. He is afebrile. He has dullness over the upper anterior aspect of his chest posteriorly. He has no Myoclonus. He is pale. His abdomen is normal. Linda looks tired but she seems to be coping so far. His last liver function tests were abnormal and an ultrasound showed two large metastases 3 months ago. CBC one month ago showed hemoglobin of 84 with normal white cells and platelets.

Please describe the careplan you would initiate at this time.

Answer:

Care Plan Considerations:

- the situation of the last hours of caring
- the signs and symptoms of dying
- the need to make a rapid assessment
- the need for family support
- the son in Calgary
- Advance Directive (remember only DNR was addressed)

Care Plan Management

A. Preparation

- a. Focus care on the patient and family as the unit of care
- b. Provide education (both at the bedside and in written form)
 - i. The signs and symptoms in the last hours (changes with dying- food & fluid, pain and dyspnea)
 - ii. The role of the family and care providers (children)
 - iii. The issues of grief
 - iv. The issues of religious customs, rites etc
 - v. The on-call back-up
 - vi. Clarifying advanced directives (No 911)
 - vii. What to do when the patient dies and how and when to reach the appropriate care provider (pronouncement process)
 - viii. Dealing with fantasies and fears around death and around the adequacy of care in the home (previous experiences- being with your loved one)
 - ix. Differing agendas among family members
- c. Be prepared to talk to Julian – impending death (if they want to), communicating feelings and last wishes/ goodbyes. As time goes on they will become less and less aware.

B. Symptom Management

1. Positioning –best position in bed that is comfortable to patient, positioning should be maintained except in last hours of life
2. Skin Care- Watch for shearing and friction forces, cleansing for comfort and massage over reddened areas however if last hours as long as patient is comfortable skin care comes secondary
3. Mouth Care- please refer to hand out
4. Pain- refer to Pain Module
5. Nutrition and Hydration- only if there is a reason for doing so
6. Secretions- Covered in previous modules- However, avoid using the term “death rattle”
7. Terminal Delirium and Agitation- refer to previous modules
8. Incontinence- urinary catheters may be best. Use diapers only if significant diarrhea or stool incontinence. Otherwise use incontinence pads on bed.
9. Medications- stop all unnecessary medications and try to foresee various other medications routes.
10. Breathing Patterns and Dyspnea – refer to module
11. Terminal Sedation- this will be covered in next study group meeting

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