End-of-Life Care

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INTRODUCTION

Dying is an individualized and personal experience. Many times, clinicians are on the front line when it comes to death and dying, so it is important to evaluate one’s own views or feelings when it comes to the death experience.

Clinicians are expected to demonstrate competency and compassionate care during this phase at the end of life. Patient preferences are important, and bedside caregivers should be advocates for patient rights and choices during this time.

The desired outcome for end-of-life care includes physical and emotional comfort for the dying patient and effective coping for the patient’s family. Keep in mind that the needs of families of patients who are dying are different from those of families who had had their loved one die unexpectedly.

PURPOSE/OVERALL GOAL

This module focuses on patients who are going through the dying process at the end of life. It includes instructions for healthcare providers on the physical, emotional, and spiritual needs of both the patient and the family, and the steps to take to support them at this difficult time.

The goal of this module is to ensure that you as a healthcare provider have the necessary skills to deliver appropriate and compassionate care to dying patients and their loved ones.

COURSE OBJECTIVES

After completing this module, the learner should be able to:

1. Describe the role of nurses in end-of-life care
2. Define pain management options for terminally ill patients
3. Define clinical assessment findings approaching the end of life
4. Describe cultural, spiritual, and legal end-of-life considerations
5. Describe appropriate postmortem care for deceased adults
**NURSING APPROACH TO DEATH AND DYING**

Clinicians should approach death and dying as a physiological, psychosocial, and spiritual event. The following should be integrated into the patient’s plan of care:

- Assessment and identification of patient/family concerns
- Promotion of an interdisciplinary approach
- Honoring and respecting patient/family wishes
- Addressing the family as the unit of care

A few examples of psychological and spiritual concerns could include:

- Fear of the dying process
- Fear of abandonment
- Fear of the unknown

Maintaining open and honest communication is vital. Statistics show that:

- 10% of all communication is understood from words
- 30% is taken from sound and tone of the communication
- 60% is taken from body language

A few things to keep in mind when communicating with the patient and the patient’s family are:

- Provide information in simple and easy-to-understand terms
- Convey a caring, sensitive, and compassionate attitude
- Maintain a physical presence during this time, which is essential
NURSING INTERVENTIONS

The role of the nurse in providing care at the end of life is multifaceted, requiring the nurse to care for the patient’s physical, emotional, and spiritual needs.

The family of the patient will also require support, as well as:
- Education about how the body changes towards the end of life
- What things they should expect to see in their loved one
- How to cope with grief and anticipation of death

In short, the nurse should:
- Promote a collaborative interdisciplinary approach
- Provide support
- Provide education
- Promote physical comfort
- Promote role model comforting
- Provide spiritual care according to patient preference
PAIN MANAGEMENT

Pain is defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage."

The objectives of palliative care are:
- To make the patient as comfortable and pain-free as possible
- To support the family during this end-of-life period

When caring for a terminally ill patient, you should:
- Anticipate pain needs and provide relief before the pain becomes severe
- Remember levels of analgesia may need to be increased due to tolerance of a variety of narcotic analgesics, in addition to progression of the disease state
- Assess the patient frequently for pain management needs
- Discuss the pain management plan with the patient and family
- Assure the family that everything possible is being done to keep the patient comfortable

Note: If you are concerned about side effects with opioids, remember that the objective of palliative care is to control pain and keep the patient comfortable. Higher-than-usual doses may be required to control the pain effectively.

You may have to be creative in finding the best solutions for individual patients, but the family and patient provide a valuable source of help. LISTEN to your patient and his/her family. The assessment and management of pain is critical.

It is also important to rule out other possible causes of pain during a pain assessment. It may be necessary to incorporate the nonverbal pain scale, if the patient is no longer able to communicate.

Some examples of nonverbal signs that a patient may be experiencing pain are:
- Grimacing
- Crying
- Moaning
- Tension
- Withdrawal
- Restlessness
- Guarded movements
- Rubbing an area
- Increased pulse, respiration, and blood pressure (non-conclusive)

It is important to remember that pain is very subjective. Pain is whatever the patient says it is. It is experienced differently by different people.
A number of factors can influence the way that different people experience pain:

- Previous experience with pain
- Meaning of pain for the individual
- Beliefs about pain
- Usual coping mechanisms
- Psychological state

The experience of pain may be influenced by the way that the patient was brought up to view and deal with pain, and by the expectations of the patient’s culture or society.

With the approaching end of life, the patient may no longer wish (or be able) to eat or drink. Families often find it hard to see their loved ones stop eating or drinking, and denial of what is happening is common and understandable.

One of the objectives during this time is to assist the family in providing alternatives ways to support the patient’s care. The family also needs support during this time and help understanding the physical changes happening with their loved one.

Comfort measures during the final hours include:

- Avoid suctioning
- Keep lips and mouth moist to help control thirst
- Change patient’s position frequently as desired
- Provide education and support to the family
EDUCATION

Educating the family is a vital component in providing end-of-life care and providing comfort during this difficult time. Consider the following:

- Education is empowerment to the family. It allows the clinician to involve the family in the patient’s care.
- Educate the family on the death process.
- Educate the family that the signs and symptoms you discuss are only a general guide and that each individual death experience is unique.

Certain clinical assessment findings approaching the end of life include the following:

- **Cardiovascular:**
  - Tachycardia
  - Hypotension
  - Peripheral cooling
  - Cyanosis
  - Mottling of skin
  - Diminished urine output

- **Neurological:**
  - Decreasing level of consciousness
  - Delirium
  - Changes in respiratory patterns
  - Loss of ability to swallow
  - Loss of sphincter control

Clinical assessment findings at the time of imminent death include:

- Oliguria/anuria
- Cold and mottled extremities
- Significant changes in vital signs
- Significant changes in respiratory patterns
- Respiratory congestion

Clinical assessment findings that confirm death has occurred include:

- Absence of heartbeat
- Absence of respirations
- Pale/cyanotic color
- Pupils fixed and nonreactive to light
- Significant drop in body temperature
- Relaxation of muscles and sphincters
CULTURAL AND SPIRITUAL CONSIDERATIONS

The dying experience is a time when people may reflect on their life. This is also a time when the clinician can act as a liaison by listening to the patient and respecting his or her wishes.

The clinician can support spiritual care by facilitating the involvement of the patient’s pastor or preferred spiritual counselor. Cultural considerations should be respected as well, and this can be accomplished by being aware of the patient’s and family’s:

- Beliefs
- Rituals
- Death rites

For example:

- Studies show that black Americans are less likely than white Americans to have an advance healthcare directive in place and commonly request that all heroic measures be instituted to save their life, believing that God ultimately controls the life of a human.
- People from an Amish culture often use herbal remedies and other complementary medical interventions at the end of life. The clinician should review these practices for potential adverse interactions with pharmacologic agents and medications.
- Jewish people may struggle with issues surrounding enteral nutrition (tube-feeding into the GI system) at the end of life, because withholding nutrition can be seen as speeding up the death process, which is forbidden by Jewish religious law. Jewish family members also may request to remain with the body of the deceased from the moment of death up to the time of burial, in keeping with Jewish tradition.

Cultural competence is a key aspect of nursing practice because nurses care for patients and families of many different cultural backgrounds. Nurses should understand the cultural beliefs, attitudes, and traditions of the patients and families they provide care for, in order to communicate effectively and provide appropriate, individualized patient care.
LEGAL CONSIDERATIONS

Every state has its own laws regarding advance directives, so clinicians should be aware of and know about the laws in the state governing their practice, as well as facility policies and procedures.

The federal 1990 Patient Self-Determination Act requires hospitals, nursing homes, and other medical institutions that receive Medicare and Medicaid funding to provide written information about advance healthcare directives to all patients at the time of admission.

Studies funded by the Agency for Healthcare Research and Quality (AHRQ) have shown that people who talked with their family, physician, or others about their preferences for end-of-life care:

- Had less fear and anxiety
- Felt more in control of their own medical care
- Believed that their doctor had a better understanding of their wishes

Other potential benefits of advance care planning, according to the National Institutes of Health, include:

- Decreased personal worry
- Decreased feelings of helplessness and guilt for the family
- Decreased implementation of costly, specialized medical interventions
- Decreased overall healthcare costs

The two types of advance directives are the living will and the durable power of attorney.

1. A living will is a written, legal document that specifies what kind of treatment a patient wants in certain situations. This may include:
   - Specific care options, such as CPR if cardiac or respiratory arrest occurs
   - Artificial feeding options
   - Prolonged use of an artificial respirator (ventilator), if unable to adequately breathe independently
   - Blood transfusions

2. The durable power of attorney for healthcare allows patients to name someone who can make medical decisions for them if they become unconscious or lose the ability to communicate. The durable power of attorney for healthcare does not appoint anyone to make legal or financial decisions.

For family members, benefits of advanced care planning include:

- Clarity regarding the patient’s wishes
- Increased comfort and decreased conflict among family members – and between family and provider – upon the patient’s incapacitation
- Preparation for eventual reflection that care plans were in agreement with patient’s values
POSTMORTEM CARE (ADULT)

Postmortem care involves care provided to the body after death has occurred, up to the time of transfer to the next facility – typically a funeral home. The nurse is responsible for performing postmortem care and usually obtains assistance from other clinical staff, such as a nursing assistant or patient care technician.

- It is important to include the family in postmortem care if they desire to assist.
- Facility policy and procedure will guide staff in the necessary steps and tasks associated with postmortem care.

During postmortem care:
- It is customary for IV lines, tubes, and catheters to be removed.
- A bed bath and skin care is normally performed before the family views the body.
- If organ donation has been pre-planned, a team will assist in any non-typical procedures or tasks that are required.

It is important to remember these key components when providing postmortem care:
- Immediately after the patient’s death, establish privacy for patient and family.
- Prepare Personal Protective Equipment (PPE), normally gown and gloves.
- Respect cultural preferences of both patient and family.
- Introduce yourself to the family, if you haven’t met before, and explain your role in care.
- Follow facility-specific policies and procedures.
- Position the body according to policy or family preference.
- Provide adequate time for family to spend with the body after care is performed.
- Prepare for removal of the body according to facility-specific policies and procedures.
PEER SUPPORT

Since healthcare providers are frequently exposed to death and dying, especially in hospice settings, it is important to establish a mechanism by which peer support is addressed and encouraged.

Some of the ways that this can be accomplished are to:

- Provide support to fellow staff members
- Help to organize rituals or memorials for patients
- Model self-care strategies
CONCLUSION

The role of the clinician is fundamental during the final stages of a patient’s life. As a healthcare provider, it is important for you to understand your responsibilities and role at this stage.

A personalized approach is essential in addressing the unique concerns that occur at the end of life, providing comfort to the patient and family, and providing compassionate care. It is accomplished most successfully when you have a history of positive communication with the patient and family and have established a trusted relationship.

REFERENCES: