Module 22 – End of Life Care

Introduction

As a home care aide, you will eventually work with an individual with a terminal illness. It is essential that you have a strong understanding of the role of hospice and how to care for the dying patient in their home. This module will explore the needs of the dying patient and your role as the home care aide.

Objectives

At the end of the module, the nurse aide will be able to:
1. Explain the concept of and criteria for hospice care
2. Describe the home care aide's role in providing care to the dying patient
3. Discuss the home care aide's role in working with the patient's family
4. Explain how cultural diversity relates to end of life care

Instructional Resource Materials

- Preface for Faculty - Teaching death and dying can be emotional for both faculty and students. It is important that the faculty be insightful of their own feelings before teaching.
- Faculty may want to consider a guest speaker from their local hospice organization. Ask the hospice guest speaker if they can share "Gone from My Sight" resource (if utilized in their organization).
- Suggestion: if your educational institution allows videos, find "Gone from My Sight," by hospice nurse Barbara Karnes, on YouTube. It is an excellent video on end of life care.
- Suggestion: ask someone from a local pastoral care department to speak about their role in end of life care. Hospitals and hospice organizations typically have a pastoral care department or chaplain.
- Power Point for Module 22 – End of Life Care
- Print Activity #1
- Print the following handouts:
  - Tips for communicating with seriously ill patients
  - Tips for talking with dying patients
  - Tips for what should you report
  - Tips for what to do when a patient dies at home
  - Tips for providing emotional support to the family
  - Tips for respecting the patient and family cultural beliefs

Module 22 – End of Life Care

Slides	Instructor's Script	Notes
Slide 1 Title Slide	**Script** • Module 22 – End of Life Care	
Slide 2	**Script** • **Objectives -** At the end of the module, the nurse aide will be able to: 1. Explain the concept of and criteria for hospice care 2. Describe the home care aide's role in providing care to the dying patient 3. Discuss the home care aide's role in working with the patient's family 4. Explain how cultural diversity relates to end of life care	
Slide 3	**Script** • Module 22-A Hospice care	
Slide 4	**Script** • What is hospice? • Hospice care is a concept or philosophy of care that focuses on patient comfort and quality of life rather than curing the patient's disease. • It is appropriate for someone with a terminal illness and life expectancy of six months or less. A terminal illness is a disease or condition that will eventually cause death. These conditions include, but are not limited to: o Cancer o Congestive Heart Failure o Chronic Obstructive Pulmonary Disease o Other cardiovascular and pulmonary limiting diseases • Hospice care is typically given in the patient's home but also may be given in inpatient hospice units. It is estimated that up to 80% of hospice care is provided in the patient's home (vs. inpatient care). • Hospice care is a team approach, with specially trained nurses, social workers, and other professionals all working with the patient to maintain comfort and dignity in the patient's last days. • Hospice care does not provide 24 hours around the clock nursing care, so many patients are either cared for by family members, hired caregivers, or nursing home staff.	
Slide 5	**Script** • Hospice Stats – U.S. hospice utilization in 2019 was 52.4%. • More than 1.55 million people in the US with a life-limiting illness received care in 2018 through hospice. • Average length of service was 77.9 days in 2018.	

Slide 6	**Script** • Guidelines for hospice admission depend on expected life span. Patients have an expected life span of 6 months or less (patient can remain in care if there is a persistent decline in health). • The patient must have a life limiting condition of which the patient and/or family are aware. • Patient/family must desire palliative care, rather than a curative focus. • Progression of disease must be documented – e.g. multiple hospital admissions, decline in functional status, impaired nutritional status. • The more symptoms a patient experiences (dry mouth, shortness of breath, problems eating, trouble swallowing, or weight loss), the more likely they are to have limited survival.	

Slide 7	**Script**
	• It is a myth that hospice is only for cancer patients; however, cancer is the most common primary diagnosis in hospice. The top cancer diagnoses are:
	  ○ Lung
	  ○ Colorectal
	  ○ Pancreatic
	  ○ Breast
	  ○ Prostate
	  ○ Liver and intrahepatic bile duct
	• To have a cancer diagnosis and be eligible for hospice, the patient must have clinical findings of malignancy with widespread, aggressive, or metastatic disease *OR* decline in performance status and/or significant unintentional weight loss.	

Slide 8	**Script**
	• Non-cancer diagnoses account for increased patients in hospice care.
	• Stays in hospice tend to be longer for non-cancer patients.
	• Non-cancer end-stage incurable illnesses or conditions seen in hospice include, but are not limited to:
	  ○ Advanced biological aging
	  ○ Adult Failure to Thrive
	  ○ HIV
	  ○ ALS (Lou Gehrig's Disease)
	  ○ Stroke and Coma
	  ○ Dementia
	  ○ Pulmonary Disease
	  ○ Heart Disease
	  ○ Liver Disease	

Slide 9	**Script** • Module 22-B The home care aide's role in providing care to the dying patient	
Slide 10	**Script** • The role you play in the life of a patient with a terminal illness is invaluable. You must take your responsibility seriously. You never know the impact of your words or actions. • It is first important to be educated on the dying process itself. This is a unique experience; however; there are often similarities to be aware of and how they may affect your patient/care for your patient. o Physical weakness and lack of energy – a weakened system carries less oxygen to muscles, making movements and physical activities hard to accomplish. This can cause a patient to withdraw from others as they feel burdensome since others now must perform tasks and ADL's for them. o Increased sleeping – this can be due to exhaustion from visitors or activities, medications, or the disease process. Simply being present with the patient can be helpful and show the patient you care. o Loss of appetite – as disease progresses, the digestive system weakens. Likewise, some medications can change the taste of foods, making mealtime unpleasant. It is normal to have a change in eating habits during the dying process – the dying patient's priorities are changing, and nourishing their bodies is not a priority anymore. o Difficulty swallowing – eating, drinking, and taking medications can be challenging when the swallowing reflex weakens. The patient may require soft foods or liquids at this point and should not be forced into eating meals or solid food. o Confusion – this can be the result of many factors, including medications, disease, or decreased oxygen to the brain. Try and reassure your patient gently and try to explain who you are and who others around you are. o Restlessness – this can be a sign that the patient is uncomfortable, in pain, or confused about something. It can also be a sign that the patient will die soon. Be sure the patient is safe and not doing harm to themselves, and just be present and calm with the patient. If the patient has a religious belief, have a pastor or priest come in to pray with the patient.	

	○ Bowel movements – incontinence is common at this point, as muscles weaken and mobility decreases. Be sure to keep the patient's skin dry and clean and keep a record of bowel movements. More than two days without a bowel movement could be problematic for the patient. ○ Body temperature – as the heart weakens and body systems start to fail, circulation and body temperature will be affected. If the patient can, let them tell you how they feel and whether they want blankets or coverings to stay comfortable. ○ Breathing – a signal of the active dying process is when a patient starts to exhale for longer than they inhale. This can happen for days or weeks before passing. Breathing then becomes irregular and can speed up. The death rattle breathing noise is created by excess saliva at the back of a patient's throat and is too far down to be suctioned. ○ Increased energy – a patient may become alert or have a spurt of increased energy a few days or hours before they die. This phase does not usually last long. • Immediately preceding death, the following may be observed: ○ Large pupils ○ Glassy eyes ○ Staring at nothing ○ Grey or blue coloring ○ Cold hands ○ Open mouth breathing, pausing between breaths, and rattling breathing sounds ○ Unresponsive to others	
Slide 11	**Script** • It will be important at this time to offer emotional and spiritual support. • Offer a listening ear and never offer advice. Patients often need to just talk about their feelings. Do not offer pat answers/statements such as, "It will be ok." • Offer quiet time. • A soft touch is often comforting.	
Slide 12	**Script** • **Activity #1** - The Dying Patient's Bill of Rights • Faculty: Print off copies of this activity. Have each student stand and read a statement (go in order). Have the student explain what that statement means to them. This can be a powerful activity if the students are willing to really think about the statement and give heartfelt answers.	

	• Alternative for Faculty: Print one copy and cut each statement out. Fold the statements and put into a hat/jar/bowl. Have each student draw a statement and do the same exercise as above. Give the students a copy of the entire sheet at the end of the exercise.	

Slide 13	**Script**
	• In providing home care to your patient, much of the same care provided to other patients could also be listed on the care plan:
	  ○ Bathing
	  ○ Grooming
	  ○ Dressing
	  ○ Changing of bed linens
	  ○ Companionship
	  ○ Assisting with meals
	  ○ And/or any other activity or duty that is assigned on the plan of care
	• Other important roles of the home care aide include:
	  ○ Comfort measures
	  ○ Personal Care
	  ○ Pain Relief
	  ○ Emotional Support
	  ○ Provide respite for the family
	  ○ Observe and report caregiver stress	

Slide 14	**Script**
	• Specific skills that will be helpful include:
	  ○ Be a good listener
	  ○ Respect privacy and independence
	  ○ Be sensitive to individual needs
	  ○ Be aware of your own feelings and beliefs
	  ○ Understand the shift from quality of life to the quality of death
	  ○ Working as a team	

Slide 15	**Script**
	• Specific skills that will be helpful include continues:
	  ○ Communication with other staff important
	  ○ The patient's final journey should be as peaceful as possible
	  ○ Offer comfort and support to family
	  ○ Remember to care for yourself, recognize your feelings and take time to reflect	

Slide 16	**Script** • **Handout #1 – Tips for communicating with seriously ill patients** • **Handout #2 – Tips for talking with dying patients** • **Handout #3 – Tips for what should you report**	

	• Give handouts to students. Review information together and discuss.	
Slide 17	**Script** • Module 22-C The home care aide's role in working with the patient's family	
Slide 18	**Script** • Death is such a large, and at times controversial, topic, and people have many different beliefs as to what happens when a person dies. Home care aides work closely with their patients at a crucial time in those patients' lives. • This can be an emotional and painful time for the person who is dying, but also for the patient's family and/or caregiver(s). Home care aides and the patient's family and/or caregivers can go through a good deal of grief during this phase. • Before the patient dies, it is common to experience what is called anticipatory grief. Anticipatory grief is the beginning of the grieving process, when we first start to prepare ourselves for someone's passing. We try to get ourselves ready for the person's death, and usually do so in a quiet, and introspective manner. • Home care aides are around ill and dying patients frequently; however, that does not mean that the worker will not experience grief for his/her patient(s). • Grief is an individual experience. It is the pain or sorrow of loss, and dreams, and experiences. It is missing someone whom you cared for. Grief lasts as long as it needs to last. It is a personal experience and will be different for everyone. Some people will grieve briefly, while others will grieve for a much longer time. There is no right or wrong way to feel grief or to grieve.	
Slide 19	**Script** • In 1969, Dr. Elisabeth Kübler-Ross outlined five basic stages of grief. 1. Denial: Refusing to believe they are going to die. 2. Anger: Often questioning why God is going to allow them to die. 3. Bargaining: "If I can live 2 more years to see my son graduate from high school." 4. Depression: A time to mourn and reflect. 5. Acceptance: A time to start to prepare for their own death. • Not everyone will go through these stages, nor will everyone go through them in the same order. People may also go back to stages if they were not fully resolved as well.	

	• Family members may react to their loved one's illness or imminent death with:
	  o Shock
	  o Denial
	  o Anger
	  o Guilt
	  o Regret
	  o Sadness
	  o Loneliness	

Slide 20	**Script** • As the dying patient's home care aide, the family will look to you for assistance in caring for the patient – this will include what is listed on the care plan, but also support, encouragement, understanding, and comfort. • It is also important to be aware of how family members are handling the upcoming death, and if that is affecting how they are caring for the patient. Be sure to report any signs of caregiver burnout to your supervisor. The family may need more education or simply some respite care. Your supervisor can assist with this process.	
Slide 21	**Script** • **Handout #4 – Tips for what to do when a patient dies at home** • **Handout #5 – Tips for providing emotional support to the family** • Give handouts to students. Review information together and discuss.	
Slide 22	**Script** • Module 22-D Cultural diversity related to end of life care	
Slide 23	**Script** • What is culture? Culture can be defined as a group's shared language, traditions, and beliefs that set that group apart from others. Those in the same culture share knowledge, behavioral norms, and values that help them live in families, groups, and communities with others. • But culture is so much more than that, with so many different layers. Subcultures also exist within any culture. For example, one could say that overall, the United States has a sense of its own culture. A few examples of subcultures within the United States are African Americans, Mexican Americans, and Vietnamese Americans. • Members of these subcultures share a common identity, dialect, food traditions, etc., all stemming from common ancestry. As the cultural differences between members of a subculture disappear, the line between being a	

	culture and subculture blur. For example, this is the case for German Americans or Irish Americans today. Most identify themselves as Americans first and consider themselves to be part of the cultural mainstream. • Culture can also define groups within countries by various other groupings, such as: o Religion (e.g. being Catholic) o Occupation (e.g. being in the military) o Geographical regions (e.g. southern culture) o Other statuses (e.g. being gay/lesbian)	
Slide 24	**Script** • Culture vs. Ethnicity – o Culture is more based on assumptions, values, and tangible signs or artifacts that outline a group's organization and their behaviors. It is the process of living in a group. It refers to the way we do things. o Ethnicity is part of a person's identity. It is the person's identity in a racial or national group. Likewise, by being a part of that group, the person identifies with that group's customs, beliefs, and language.	
Slide 25	**Script** • Culture, Religion, and Spirituality – o Culture is more based on assumptions, values, and tangible signs or artifacts that outline a group's organization and their behaviors. It is the process of living in a group. It refers to the way we do things. o Religion is the adherence to an organized set of beliefs. This is also called faith and typically includes a higher being or beings. Religion impacts a person's lifestyle and behaviors, and often gives people focus, comfort, and meaning. o Spirituality deals more with a person's perception of his/her reason for being, for who we are and how we are. It can be influenced by religion, culture, and science.	
Slide 26	**Script** • Why learn about culture, ethnicity, and/or religion? • Recent studies have shown that patients in the U.S. are requesting more attention to the spiritual dimensions of their lives by health care providers, especially end of life care. Therefore, it is important for the home care aide to familiarize themselves with the patient's religious or culture beliefs/practices as they may play a role in health care decisions. These beliefs/practices should be included or integrated into the patient's overall plan of care.	

	• For end of life care, alleviating physical pain is only part of the health care team's goal. Social, emotional, and spiritual suffering are equally important.
	• Understanding a patient's belief system builds trust and respect.
	• Likewise, if a patient chooses to refuse a certain aspect of his/her care, this conflict might be better understood and rectified or worked around.
	• As home care aides, and any other professional who works with individuals and families, it is of utmost importance to have some sort of understanding of the values and beliefs of the person you are caring for.
	• For a home care aide to show sensitivity and understanding, especially while one faces death, can make all the difference while caring for a patient. It can be hard at times to look past preconceived notions, ideas, or stereotypes. Therefore, to educate oneself on other cultures can broaden your understanding of not only one's patients, but also entire groups of people who you may not have fully understood before.
	• Being culturally sensitive during end of life care will help you to understand:
	  ○ Relationships
	  ○ Roles within the family
	  ○ Support systems
	  ○ End of life decisions
	  ○ How religious views/affiliations can affect end of life care decisions	

Slide 27	**Script** • As a home care aide, you will encounter a patient whose beliefs are different than your own. • What is important is what you do when your beliefs are different than your patients. • Always be respectful. Never challenge your patient's beliefs or debate with him/her. It is okay to nicely say to someone, "I respect that your thoughts on that matter are different than my own; however, I am here to care for your health and I hope we can focus on that." • As always, your supervisor is there for you to discuss issues with as well. If you need help dealing with your personal feelings towards a patient, your supervisor can help you with that. • Keep an open mind. You are not going to change your beliefs, and chances are your patient will not either. Therefore, do not attempt to engage your patient in debates or discussions. That is not your role and can lead to distress and distrust in your patient. • Try to look at the interaction as a learning experience. You might gain a better understanding of a certain	

	culture and can apply that knowledge down the road with other patients or share with co-workers.	
Slide 28	**Script** • **Handout #6 – Tips for respecting the patient and family cultural beliefs** • Faculty: Give handout to students. Review information together and discuss.	
Slide 29	**Script** • Working with patients with terminal illnesses can be exhausting and draining, but it can also be rewarding and fulfilling. Be aware that you are present during one of the most significant times in a patient's life, and the family of the patient may be going through a variety of emotions. Being sensitive, observant, and supportive will never be needed more than at this time.	