Frequently asked questions about palliative care

Nurses can serve as leaders as they help patients and families through a difficult time.

By Kaveri M. Roy, DNP, RN

PALLIATIVE CARE MEASURES for patients with serious or end-stage illnesses can be confusing and lack clarity. Typically, patient care goals focus on curative measures, and patients and families may not be familiar with palliative care. To complicate matters, patients, families, and even providers frequently associate palliative care with imminent death and "giving up." However, when we understand the effects of a disease, its interventions, and know patients' care goals, we can be better patient advocates across the spectrum of care. We can serve as nurse leaders on an interprofessional team to manage patient and family care and help patients and their loved ones cope with the disease process. Here we address some commonly asked palliative care questions.

What is the biggest issue for patients with serious or end-stage illness?

Managing symptoms and side effects of the disease process and its treatment typically is the primary goal of patients who are seriously ill or dying. Palliative care focuses on improving patient quality of life and is available to all patients with a serious or end-stage illness, whether or not they're receiving curative treatment.

According to the American Nurses Association's *Call for Action: Nurses Lead and Transform Palliative Care*, all nurses should be prepared to provide primary palliative care according to the eight domains outlined by the National Consensus Project for Quality Palliative Care. (See *8 domains of palliative care*.)

What are the most common signs and symptoms, and how are they treated pharmacologically?

Patients may experience signs and symptoms related to disease progression, treatment, or both. Common physical symptoms are pain, dyspnea, nausea, anorexia/cachexia, and constipation. Nurses also should assess patients for psychological and spiritual symptoms, such as delirium, anxiety, and spiritual unrest.

Even if patients are unconscious or sleeping, symptoms such as pain, anxiety, and dyspnea don't abate. In unconscious patients, signs and symptoms may manifest as brow furrowing, clenched teeth, vocalizations, and tachycardia. Medications must be continued for patient comfort.

Pain

Patients can have somatic, visceral, and neurologic pain, or a combination. Mild pain can be treated with acetaminophen or nonsteroidal anti-inflammatory drugs (NSAIDs), and moderate pain with hydrocodone, oxycodone, acetaminophen, and NSAIDs. Severe somatic or visceral pain typically is treated with opioids, starting with an oral low-dose medication, such as morphine (2.5 to 5 mg every 6 hours), and slowly titrating based on the patient's pain level. With severe or end-stage illness, pain likely will progress. Reassess the patient's pain level frequently. If the patient is using p.r.n. pain medication frequently, a long-acting medication (such as MS Contin) may be ordered. Continuous I.V. or subcutaneous opioid infusions may be ordered for severe pain.

Hydromorphone and hydrocodone can be used p.r.n. for breakthrough pain, but multiple types of opioids should not be used concurrently. Using a consistent p.r.n. or breakthrough medication is important when titrating long-acting medication because the amount of

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LEARNING OBJECTIVES

1. Discuss pharmacologic strategies for relieving distress in patients with serious to end-stage illness.
2. Discuss nonpharmacologic strategies for relieving distress in patients with serious to end-stage illness.
3. Identify the stages of death.

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p.r.n. medication taken within 24 hours can be used to start or adjust long-acting medications. Using a consistent p.r.n. medication also can prevent adverse effects. Fentanyl patches can be used for long-acting pain management, but be cautious; patches can't easily be titrated, and the patient must have a sufficient amount of subcutaneous fat for the medication to be effective. Patients who are thin or emaciated run the risk of absorbing the medication too quickly.

For patients with neurologic pain, adjuvants such as gabapentin, tricyclic antidepressants, or low-dose methadone may be ordered. Methadone is considered effective for neurologic pain and builds up to a stable concentration in the blood, functioning as a long-acting medication. Note that as methadone builds to a therapeutic concentration, faster-acting medications for pain control must be used and titrated down as the methadone takes effect.

Dyspnea

Dyspnea is a common end-of-life symptom. Typically, it's associated with lung and heart diseases, such as chronic obstructive pulmonary disease (COPD), lung cancer, and chronic heart failure (CHF). Patients with end-stage lung disease will require oxygen. Adding bronchodilators and steroids can help relieve chest constriction and lessen dyspnea. Low-dose opioids (such as morphine) also relieve dyspnea, but the exact mechanism of action is unknown. Continuous opioid infusions also can be given for severe dyspnea.

To address the anxiety that may accompany dyspnea, the provider may order an anxiolytic such as a short-acting benzodiazepine (for example, lorazepam and alprazolam) to control dyspnea or prevent it from worsening. If a patient is dyspneic but not hypoxic, which occurs with cancer and some other disease processes, oxygen may not help manage symptoms.

For CHF exacerbation, the provider may order oral, subcutaneous, or I.V. diuretics (for example, furosemide) to drain excess fluid and help ease breathing. Oxygen and opioids also may help reduce dyspnea for patients with CHF, and nitroglycerin will decrease cardiac preload and afterload.

Many patients have both CHF and COPD. A complete assessment will help determine which condition is exacerbated and which symptoms to treat.

8 domains of palliative care

The National Consensus Project for Quality Palliative Care outlines eight domains of care, which are supported by the American Nurses Association.

1. **Structure and processes of care.** Providing care via an interprofessional team based on the patient's and family's care goals
2. **Physical aspects of care.** Treating physical symptoms, such as pain and nausea
3. **Psychological aspects of care.** Treating psychological symptoms, such as anxiety and depression
4. **Social aspects of care.** Assessing caregivers, family, friends, social network; communicating prognosis
5. **Spiritual aspects of care.** Assessing spiritual or religious beliefs, hopes, and fears
6. **Cultural aspects of care.** Assessing customs, language, and belief systems
7. **Care of patients at the end of life.** Recognizing imminent death, being present, and educating patient and family about what to expect
8. **Ethical and legal aspects of care.** Identifying healthcare proxies and using advance directives

Nausea

Different disease processes (such as a bowel obstruction) and treatments (such as chemotherapy) can cause nausea and vomiting. Assessing the cause of the nausea will determine the best antiemetic treatment.

If the nausea is chemotherapy-related, serotonin 5HT3 antagonists, such as ondansetron, work well. However, after treatment ends, ondansetron won't work as well. The best antiemetic agent for patients with end-stage disease is haloperidol, which blocks the dopamine receptors and decreases nausea.

If nausea and vomiting are related to constipation or a partial bowel obstruction, a prokinetic agent (such as metoclopramide) may be ordered. Metoclopramide will cause GI muscle contraction and decrease gastric emptying time, propelling gastric contents forward and relieving a partial obstruction. However, it shouldn't be used if the patient has a complete bowel obstruction; the obstruction must be removed. If that isn't possible, I.V. octreotide, which increases gastric emptying time and inhibits gastric hormones, may be used to relieve intractable vomiting.

Anorexia/cachexia

Loss of appetite and weight loss are distressing symptoms for patients and their families. Patients may not feel like eating because of nausea, medications, or disease complications, and it can be hard for both patients and

families to let go of mealtime traditions.

Interventions are based on the patient's illness stage and care goals. If the patient has a serious illness and is continuing to receive curative treatment, gastrostomy-tube feeding or total parenteral nutrition may be ordered until the patient can eat on their own.

Families of patients with an end-stage disease may worry about "starving the patient" and encourage them to eat, causing distress for everyone. Nurses can help by explaining that the body is beginning to "shut down" and can't process the same amounts of food and fluid as before. Artificial hydration and nutrition aren't recommended at end of life because the body can't absorb the fluid or nutrients, resulting in pulmonary edema, aspiration pneumonia, or diarrhea.

Some medications can improve appetite, but their effects vary and are short acting. Before these medications are prescribed, a thorough assessment should be performed to ensure the loss of appetite isn't caused by delayed gastric emptying or constipation. Steroids, such as dexamethasone, frequently are ordered because they increase appetite. Tricyclic antidepressants (such as mirtazapine) also may be prescribed as appetite enhancers. Many patients use cannabinoids, such as dronabinol and medical marijuana, for nausea and appetite enhancement.

Constipation

Many patients with serious and end-stage illnesses experience constipation caused by a bowel abnormality or obstruction, fecal impaction, dehydration, limited mobility, or opioids prescribed for pain management. Best practices in hospice and palliative care recommend that patients taking opioids must have a prophylactic bowel regimen. If constipation isn't treated, it can lead to obstipation and increase the risk for peritonitis.

Bulk-forming agents, such as psyllium, should not be used to treat constipation in patients who are seriously ill or dying; these agents absorb water and can cause dehydration, exacerbating constipation. Oral laxatives and stool softeners, such as docusate sodium, magnesium citrate, and polyethylene glycol are recommended instead. If a patient hasn't had a bowel movement after 3 days of oral laxatives, a rectal suppository may be ordered. If the patient still doesn't have a bowel movement, perform a digital rectal exam to check for fecal impaction. Impactions should be removed; if no impaction is found, an enema may be given.

Delirium

Delirium can be hyperactive, hypoactive, or a combination. It can manifest as hallucinations, delusions, paranoia, agitation, lethargy, apathy, and slowed speech and thought.

First assess the patient to rule out reversible causes, such as drugs and uncontrolled pain. If the patient is at end of life and all reversible causes have been ruled out, they likely have terminal delirium.

Terminal delirium is part of the dying process and manifests as emotional and physical restlessness. It can't be reversed, but it may come and go. Sometimes, the patient may calmly talk to people who died long ago, and no intervention is necessary. At other times, the patient may be agitated and unsafe. Agitation treatment includes medications such as haloperidol and quetiapine. Haloperidol is the most effective treatment, but it can't be given to patients with Parkinson's disease because it lowers the seizure threshold. In these patients, quetiapine is recommended.

Anxiety

All patients with serious or end-stage illnesses should be assessed for anxiety. Pharmacologic treatment typically includes a short-acting benzodiazepine.

Do opioids hasten the dying process or cause addiction?

No evidence exists that opioids, when used according to established dosing guidelines, hasten the dying process. In fact, treating pain effectively has been shown to increase lifespan and quality of life. Legally and ethically, providers have a duty to provide opioids for symptom relief at the end of life, and a provider's fear of death as a consequence doesn't justify withholding these medications.

Patients and their families may fear opioid addiction. However, the rate of addiction is extremely low in patients who are seriously ill or dying. The more common issue is pseudoaddiction, which refers to drug-seeking behavior caused by inadequate pain management. As patients becomes tolerant to a certain dose, or the pain worsens, reassess their pain regimen and advocate for dosing that manages pain adequately.

What nonpharmacologic measures can be used for symptom relief?

As nurses, our scope of practice includes facilitating a healing environment for patients and families. In addition to administering medication, we should consider nonpharmacologic comfort measures, including creating a calming environment, positioning patients comfortably, and facilitating frequent oral hygiene. (See *Comfort measures*.)

What is the role of the interprofessional team?

An interprofessional care team for patients with serious and end-stage illnesses typically includes physicians, physician assistants, nurses, nurse practitioners, social workers, case managers, chaplains, physical therapist, dietitians, and aides. In many cases, nurses serve as case managers or liaisons, coordinating care among the different disciplines.

The team takes a holistic care approach, addressing the patient's medical, nursing, psychosocial, and spiritual needs. In addition to helping the patient and family, this approach provides support and a range of expertise to ensure the team provides optimal care. Working on a team also helps ensure everyone is on the same page.

What are the stages of death?

Signs and symptoms of dying will vary among individuals; however, with many end-stage illnesses, they typically fall within three stages: declining, transitioning, and actively dying.

Decline doesn't have a definite time frame but typically starts a few months before death. Patients may be unable to complete activities of daily living, and they frequently feel much more fatigued than at baseline.

Transitioning occurs weeks to a month before death. At this stage, patients' food and fluid intake decreases (they begin taking only bites of food and sips of fluid), they spend more time sleeping, and they may exhibit signs of delirium (for example, confusion, agitation, and talking to people who have died).

Actively dying starts hours to days before death. Common signs are decreased consciousness, breathing pattern changes, dark urine, and terminal delirium.

How can I tell if someone is dying imminently?

Signs of imminent death vary among patients, but some hallmark signs are common.

Breathing changes

Respiratory changes frequently occur at end of life. Patients may have an irregular breathing pattern (Cheyne-Stokes respirations) in which the respiratory rate becomes progressively faster and deeper, then decreases, ending with a period of apnea. "Guppy breathing," also seen at end of life, consists of shallow, rapid, agonal breaths. Dyspnea is

Comfort measures

Keeping patients and their families comfortable during a serious or end-stage illness is a primary nursing goal. Consider these suggestions for achieving that goal.

- Keep the patient's environment calm, cool, and quiet with low lighting.
- Apply heat, ice, compression, and/or elevation to help alleviate pain.
- Place the patient in a comfortable position (for example, tripod, Fowler, semi-Fowler).
- Play soothing music or the patient's favorite music.
- Use guided imagery, reiki, or massage to reduce pain or dyspnea.
- Speak to the patient in a calm and reassuring manner.
- Listen to patients and family members.
- Provide culturally sensitive care.
- Facilitate frequent oral hygiene and keep fluids fresh.
- Determine the patient's food and beverage preferences.
- Advise smaller, more frequent meals to help reduce gastric distress.
- Reorient patients having delusions if possible, but don't argue with them.
- Include the family in the patient's care plan.
- Encourage family members to talk to the patient, even if he or she is unconscious.
- Provide adequate education and frequent check-ins with patients and families about treatments, prognosis, symptom management, and medication regimens.

common, even when patients are unresponsive, and it should be managed with sublingual or injectable morphine.

Audible congestion ("death rattle")

At end of life, the muscles of the jaw relax, the patient may swallow infrequently, and the mouth may hang open, resulting in oropharyngeal secretions collecting at the back of throat. The fluid vibrates during breathing and "rattles." This isn't uncomfortable for the patient, but it may be distressing for the family. Rather than suctioning the patient, which will increase secretions, reposition them and elevate the head of the bed. Medications such as scopolamine, glycopyrrolate, and hyoscyamine (sublingual or injectable) may be ordered to help dry secretions.

Decreased level of consciousness and terminal delirium

As the patient gets closer to death, mental status changes are common. Patients may withdraw socially, sleep most of the day, and become more unresponsive. They may experience terminal delirium, a state where they become more restless, agitated, and/or hallucinate. Terminal delirium can be managed with medication and environmental changes.

Extremity cooling, pallor, and mottling

Closer to death, blood is shunted away from the extremities to core body organs (heart, brain, lungs). When this happens, the extremities will cool, pulses will weaken, and the skin will become pale and mottled. These signs aren't seen with every patient, but they can indicate that death is imminent.

Decrease in food and fluid intake

As the body starts to shut down, patients decrease food and fluid intake. Family members may think the patient is being starved. Talk to them about the dying process so they understand that this is normal. Offer the patient food and fluids for comfort. Use mouth swabs to moisten the mouth, and provide oral care. Consider dipping swabs into the patient's favorite foods (in liquid, soup, or puree form), so that they can enjoy the flavor even though unable to eat.

Decreased fluid intake will reduce urine output, which will be dark in color. This natural dehydration may cause a fever. Use cool compresses on the forehead, axilla, and groin to keep the patient comfortable, and administer acetaminophen orally or rectally if tolerated.

Urinary and fecal incontinence

While imminently dying or upon death, urethral and anal sphincter relaxation occurs, which can cause urinary and fecal incontinence.

How can I best support family?

Nurses play a major role in providing support and reassurance to the family and caregivers, both in home and long-term care settings. Family members who want to do more for their loved one may feel helpless and alone. Education is key to helping them feel supported and part of the care plan. Teach family members and caregivers about the disease process, the stages of dying, and what to expect. Provide detailed instructions and reasons for any treatments or medications they need to give. Also, teach them to assess and treat the patient for signs of discomfort.

Death is overwhelming, so provide ongoing family and caregiver education; they may not grasp everything the first, second, or even third time they hear it. Provide reassurance that they're doing a good job caring for the patient. Friends and family may be afraid to talk to dying patients. Let them know that they can continue to talk with the patient as they normally would, even if they aren't conscious. Encourage them to be open and honest about how they feel.

Easing distress

Death is a process that's frequently hidden away in our culture. Watching someone die can be stressful and scary to family and friends. As nurses, we can help patients and families cope with the dying process. We can help them establish a "new normal" and ensure that loved ones understand when the patient is comfortable. This can provide a great source of relief. AN

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Visit myamericannurse.com/?p=66918 for a list of references and a mnemonic for the reversible causes of delirium.

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Please mark the correct answer online.

1. Sam Jones*, a 45-year-old man dying of spinal cancer, states he is having severe pain. Which of the following would be an appropriate pharmacologic choice?

a. Lorazepam
b. Acetaminophen
c. A nonsteroidal anti-inflammatory drug (NSAID)
d. An opioid agent

2. An appropriate adjuvant to help manage neurologic pain is

a. hydromorphone/hydrocodone.
b. ibuprofen.
c. gabapentin.
d. high-dose methadone.

3. Which statement about the use of fentanyl patches to treat pain in patients with end-stage disease is correct?

a. They are used for short-acting pain management.
b. They are used for long-acting pain management.
c. They can be used in patients of any size.
d. They are easily titrated.

4. Mr. Jones is experiencing breakthrough pain. Which of the following might help control it?

a. Hydrocodone and hydromorphone
b. A tricyclic antidepressant
c. High-dose methadone
d. An NSAID

5. A patient with end-stage disease develops chronic heart failure (CHF). Which drug will help reduce cardiac preload and afterload?

a. Nitroglycerin
b. Lorazepam
c. Furosemide
d. Acetaminophen

6. Mr. Jones reports frequent episodes of nausea and vomiting, which his provider suspects is related to constipation. Which of the following would be an appropriate drug?

a. Haloperidol
b. Ondansetron
c. Octreotide
d. Metoclopramide

7. Which of the following statements about treating Mr. Jones's constipation is correct?

a. An enema is the first-line treatment for constipation.
b. Bulk-forming agents, such as psyllium, should not be used.
c. Stool softeners, such as docusate sodium, should be avoided.
d. A rectal suppository may be ordered after 24 hours of oral laxatives.

8. Mr. Jones's vomiting becomes intractable when he develops a bowel obstruction. If surgery isn't possible, his provider may order

a. haloperidol.
b. ondansetron.
c. octreotide.
d. metoclopramide.

9. Mr. Jones starts taking only sips of fluid. He also becomes confused and periodically talks to his father, who died 10 years ago. Mr. Jones is considered to be in what stage of death?

a. Decline
b. Transitioning
c. Active dying
d. Stable

10. All of the following indicate that Mr. Jones is actively dying, *except*:

a. tightening of jaw muscles.
b. cool, mottled skin.
c. dark urine.
d. fecal incontinence.

11. Mr. Jones is actively dying, and oropharyngeal secretions are collecting in the back of his throat. Which of the following is an appropriate action for you to take?

a. Elevate the head of the bed and give hyoscyamine as ordered.
b. Put the bed flat and administer scopolamine as prescribed.
c. Suction Mr. Jones every hour and more often as needed.
d. Suction Mr. Jones every 2 hours and give glycopyrrolate as ordered.

12. You have cared for Mr. Jones for several weeks and want to keep him as comfortable as possible. Take 5 minutes and think about what strategies you could use to ease his discomfort. Consider the types of symptoms he might have and the nonpharmacologic comfort measures that you could implement.

13. Mr. Jones is married with a 16-year-old son and a 22-year-old daughter. Take 5 minutes and reflect on how you can best support them. What emotions might they be feeling? What education would they need? How would you determine communication preferences?

*Name is fictitious.