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Fearing the final dose: Calming the trepidation nurses have caring for patients at the end of life

Nurses caring for patients at the end of life should walk away from their shift knowing that they did their best to keep the patient and their family comfortable, educated, and supported.

By Jennifer A. Carolan, BSN, RN, CHPN

Nurses often don't receive adequate training to care for patients who transition to Comfort Measures Only (CMO). The similarity between CMO and Hospice is that both focus on comfort care rather than curative. CMO is the term given to patients in the hospital setting when either the patient or the designated healthcare proxy has decided to no longer receive interventions to prolong life, whereas Hospice is an interdisciplinary benefit the patient or the healthcare proxy can choose to support their life-limiting illness. The decision to convert a patient to hospice or CMO is made when a provider concludes that there are no further interventions to "cure" the patient and they foresee their terminal diagnosis ending their life within 6 months. Alternatively, the patient decides they no longer wish to pursue curative measures and chooses comfort.

Nurses' lack of training on CMO and hospice measures is a detriment to the

nursing profession because patients and their families look to the nurse for their knowledge, guidance, and skill. Nurses are the frontline healers, comforters, and patient advocates. Without proper end-of-life training, nurses lack the confidence necessary to provide the care their patients deserve.¹ If you ever nodded off for 10 minutes in nursing school, you may have missed the brief lecture on caring for patients at the end of life.

Minimal time is dedicated to preparing nursing students for the inevitable job of caring for a patient who has transitioned to end-of-life care. Too often, we find ourselves unprepared to follow the common signs, symptoms, medications, and education required to support the loved ones of these patients.² Nurses spend an entire semester and clinical rotation learning about and caring for new parents and their infants as they enter the world. In contrast, the time dedicated to teaching nurses how to care for patients and



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educate their families at end of life is inadequate and it shows. Because nurses interact more with patients than health-care providers, it's important that new nurses be educated on end-of-life issues.³

End-of-life education

The rapidly aging population of the US, coupled with the frequency of chronic diseases, calls for broader end-of-life care education.² End-of-life nursing is a specialty that requires assessing the nonverbal signs and symptoms of end of life and advocating for and providing the appropriate patient interventions. The nurse's assessment and interventions are as important as the skilled care given to the patient and the education and support given to family members.⁴

Some nurses aren't comfortable caring for patients at end of life, either because they fear their own mortality, or they're uncomfortable having conversations about death with patients and/or their families.³ Throughout most of the nursing specialties, the nurse will be expected to care for a patient who was either given a terminal diagnosis or has an acute change in status that will require the care team to change the focus from curative to comfort. Walking into the room of a dying patient and speaking honestly and compassionately to the family or friends sitting at the bedside is a skill that takes time and practice. Confidence in having these delicate conversations with patients and their loved ones grows with experience and

self-reflection by assessing one's own clinical and interpersonal skills. Training nurses on end-of-life care can diminish their anguish and boost their confidence as they care for patients who are declining, while also supporting their families.¹ Families look to the nurse to explain what they're seeing physically as their loved ones decline and what interventions are being done to keep their loved ones comfortable. Continuing communication between the healthcare staff and the patient/family is important to nurture a mutual understanding.⁵

Oftentimes, family members have never witnessed anyone die and they may be apprehensive about remaining in the room. The nurse should assess the family member's comfort level and educate them on the signs and symptoms of imminent death. Advocating for the patient's needs over the needs of their family can be a difficult conversation to have with families. Many family members don't want the patient to be medicated (which may cause sedation) because they want them to remain awake and able to talk with them.

It's the role of the nurse to educate the family about the fine line between sedation and alertness while maintaining the goal of comfort. Informing the family that the patient will still hear them may alleviate their fears of medication administration. Establishing proficiency and confidence in providing patient- and family-centered care when they struggle with their emotions is a skill the nurse expands with experience.⁶ Verbal nursing education is key,

but for those who may be better visual learners, a great resource often given to family and friends at end of life is the pamphlet, “Gone From My Sight, The Dying Experience,” written by Barbara Karnes, RN.⁷ It describes what the patient is experiencing in their final weeks, days, and hours without overcomplicated medical jargon. Reading the explanations for what they’re experiencing when sitting at their loved ones’ beside may help quell any preconceived notions they may have about death.

Common misconceptions

There are many misconceptions about hospice and end-of-life care, including that patients no longer get out of bed, sleep all the time, and no longer eat or drink. Additionally, it’s commonly thought that the patient is giving up. It’s often assumed that once a patient’s care status is changed to CMO, their regular medications are stopped and morphine is started, which makes them somnolent and hastens death. It’s the responsibility of the provider and the nurse to have open conversations with the patient and their family regarding misconceptions and the goals of care.

Another key feature of this conversation is the opportunity to educate the patient on the risks and benefits of stopping or continuing certain medications. Weighing the benefits and risks of medications and interventions is important to increase the patient’s engagement so they’re actively involved in their care.⁸ The hospice benefit can sometimes extend a patient’s life because of the great one-on-one care they receive, especially if it’s in the comfort of their own home. A seasoned hospice nurse can provide the mentoring needed for novice nurses caring for patients at end of life or choosing to enter the specialty.

Case scenario

In the spring of 2020, the cardiac unit where my colleagues and I worked was

forced to quickly transition our space into a negative pressure room for patients with COVID-19. Prior to working on this cardiac unit, I had worked as a hospice nurse. During this intense time, compromised by a then-unknown virus, we were faced with caring for many patients who were quickly designated to CMO. Families weren’t allowed to visit loved ones, so it was up to us to hold the hands of patients as they took their last breaths. Our education and support for families were conducted virtually instead of in person—atypical even to this seasoned hospice nurse. The nurses on the unit developed the acronym, W.W.J.D. (What would Jen do?) when caring for their CMO patients. My hospice skills, knowledge, and interventions became a vital support to my team members who weren’t accustomed to providing care to so many CMO patients at once.

The final dose

During this time, many of the nurses were apprehensive about administering the scheduled comfort medications, such as morphine and lorazepam. They would say, “The patient looks comfortable, they don’t need it.” I found that this was a notable teaching point. I’d explain that the reason why the patient didn’t look like they needed medication was because they had been receiving the scheduled medication on a regular basis; therefore, symptoms were well managed. I explained that if the scheduled medication(s) were to be held, the patient could go into a pain crisis or agitated state. It’s the nurse’s judgment to hold an “as needed” medication when the patient can’t verbalize pain or anxiety; further assessment of the dying patient is crucial. The fear of giving “the final dose” is an apprehension of many nurses, but as I tell new and seasoned nurses, “Your patient is dying, you cannot change that, but by giving these medications, you are helping them die comfortably.”



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Signs of end of life

As a hospice nurse for the past 11 years, my confidence in caring for dying patients while educating and supporting families throughout their loved one’s journey has improved because I’ve learned that my advocacy and interventions have contributed to most patients and families finding acceptance and peace in the end. Caring for a patient at end of life requires the nurse to use four of the five senses:

1. Sight. Look at the patient’s breaths and facial expressions. Rapid breathing, grimacing, restlessness, and frowning of the brow are nonverbal indicators of pain, respiratory distress, and possibly urine retention or constipation, requiring immediate intervention. Look for changes in skin color. Mottling, which often shows in the fingertips and toes, is a sign that the patient’s circulation is decreasing, and the blood is pooling in certain areas.

2. Hearing. Listen for noisy breathing, audible secretions, and moaning from the patient.

3. Touch. Feel the patient’s skin. It’s very common for a patient to be febrile at the end of life. Start by using a cool cloth placed on the patient’s forehead, a light sheet, and if available, a fan on a low setting. The patient’s extremities may also feel cool to the touch as their blood circulation decreases.

4. Smell. If the nurse detects malodorous breath of a patient, it can be an indicator that death is imminent. Diligent mouth care is important to decrease oral

secretions, keep the mouth and tongue moist, and lessen any odors.

Common comfort medications

“Solid evidence is lacking to guide optimal pharmacotherapy in most end-of-life settings, especially in non-cancer diseases and very old patients.”⁹ There are common medications used at end of life to treat symptoms, such as pain, respiratory distress, terminal delirium, tracheal secretions, nausea, and anxiety. Opioid medications, such as morphine and hydromorphone, work well for management of both pain and air hunger (see *Initial opiate dosages for moderate to severe pain or dyspnea*). Lorazepam and haloperidol work well for management of anxiety and terminal delirium, and even have an antiemetic component. Terminal delirium may happen at any time during the dying process. One minute your patient is somnolent and the next minute they’re delirious, tearing off their clothes, trying to get out of bed, and falling to the floor.¹⁰

Early interventions of medications and decreasing stimuli in the room are crucial to keep the patient and staff safe because some patients may become so agitated that they develop aggressive behavioral symptoms. Oropharyngeal secretions, sometimes referred to as “the death rattle,” can be distressing for loved ones to hear. Nurses can advocate for scheduled diuretics to continue, especially if the patient has a history of congestive heart failure, because these medications

Initial opiate dosages for moderate to severe pain or dyspnea¹¹

Medication	Oral dose	I.V. or subcutaneous dose	Initial dosing frequency
Fentanyl	NA	25 to 100 mcg	Every 2-3 hours
Hydromorphone	2 to 4 mg	0.5 to 2 mg	Every 3-4 hours
Morphine	2.5 to 10 mg	2 to 10 mg	Every 3-4 hours
Oxycodone	2.5 to 10 mg	N/A	Every 3-4 hours

decrease secretion formation. These medications can be crushed and administered orally with a little bit of water in a syringe. Medications commonly used to treat upper airway secretions are atropine drops, hyoscyamine tablets or liquid, glycopyrrolate tablets or injection, and scopolamine patches.¹¹ (See *Medications of excessive oral secretions*.) Positioning the patient flat and on their side can also help for natural draining of secretions. Place a disposable absorbent pad or a towel by the patient's mouth to protect their clothing and bedding.

Many families are hesitant to have their loved one medicated because some adverse reactions of these medications include lethargy and somnolence, and they want to talk with their loved one without them being too sedated. Education regarding risk over benefit requires the nurse to help the family understand the importance of elevating the patient's comfort above their need to continue having conversations with the patient. The approach of the nurse to empathize with the family is important, so they understand that the nurse's priority is the comfort of the patient.

Nutrition and hydration

As patients near end of life, they stop eating and drinking. It's common and part of the dying process. Families, especially families in which food is the basis of their culture, have a very difficult time accepting that their loved ones are no longer eating, often saying, "You're starving him/her!" Educating the family about the patient's risk for aspiration, which would

lead to an uncomfortable death, is a priority, while also suggesting ways that the family members can express their love to the patient as they're declining. It's said that hearing is the last sense "to go," and the nurse can encourage the family to reminisce and tell stories about past family memories or vacations with their loved one. Encourage touch, whether it be hand-holding or stroking the patient's forehead. Offer alternatives for the family to show their love other than through food.

I.V. fluids are contraindicated in end-of-life care. Circulation decreases as patients are dying. Again, starting I.V. fluids for hydration, like holding medications so that families can continue to converse with their loved ones, can be more of a risk than a benefit to the patient. Often, I.V. fluids in the dying patient can cause fluid overload, such as pleural effusions and third-spacing, because the fluid isn't processed normally due to the decrease in normal circulatory function.

Environment

The patient's room should be set up in a way that's personal to them. Taking the time to ask the patient, when possible, or their loved ones what type of music they prefer so it can be played softly in the room, or what beverage they love so you can put it in with ice chips, shows the family you care about the person. It's amazing how many rooms of patients who are dying don't have a box of tissues available. Family and friends grieve in different ways. Some show anticipatory grief by crying, others may sit in silence and don't want to speak to

Medications of excessive oral secretions¹¹

Medication	Dosage (as needed)
Atropine ophthalmic 1% drops	1 or 2 drops sublingually every 6 hours
Glycopyrrolate	1 mg orally or 0.2 to 0.4 mg subcutaneously or I.V. every 4 hours
Hyoscyamine	0.125 to 0.5 mg sublingually or subcutaneously every 4 hours
Scopolamine transdermal patch	1 or 2 1.5 mg patches applied every 72 hours

anyone. We need to honor how people grieve but let them know we're there not only for their loved ones but also for them.

Check on your patient. When you receive your assignment at the start of your shift, check on your end-of-life patient first. The end-of-life patient is the priority of your shift assignment because they're dependent on you to assess them frequently and provide the appropriate interventions to maintain their comfort. Collaborate with the unlicensed assistive personnel to determine a time you can provide care once you've premedicated the patient. It isn't necessary to turn and reposition a patient every 2 hours at end of life. Moving a dying patient approximately twice per 8-hour shift can help with movement of secretions and incontinence care.

As patients decline, they tend to mouth breathe. This causes dry mouth with potential odor. Mouth swabs with the patient's favorite beverage on ice works well to keep the mouth moist. The nurse can teach the family and/or friends how to swab the patient's mouth, especially if they're wanting to be involved in their care. It's important to squeeze the swab on the side of the cup to avoid placing too much liquid in the patient's mouth. Apply mouth moisturizer frequently. Note that if the patient is on oxygen, moisturizers containing petroleum are contraindicated because they're combustible. Place a basin in the side table because, depending on the patient's diagnosis, vomiting can happen at any time.

If the patient or family has brought in pictures, place them on whatever side the patient is facing. The patient may open their eyes and find comfort in seeing the pictures of their loved ones. Talk with your patient. As mentioned, hearing is said to be the final sense to leave the patient. Just like you would explain everything you're doing or every medication you're giving to your alert and oriented patient, do the same for your patient who's actively dying whether there's family present or not. The nurse's soothing voice contributes to keeping the patient and their family calm.

In my experience, being honest with the patient and their family helps to foster trust. Many families ask the ultimate question, "How much longer?" We don't have a crystal ball, but the more you care for patients at end of life, the more familiar you become with the signs of imminent death. It's helpful to tell family members updates such as, "If you want to be present when they die, you should stay."

Honesty must come with compassion. Self-reflection by the nurse is an important tool so they can put themselves into the shoes of the families they're supporting. Ask the loved one if they've ever seen anyone die before. Some people are uncomfortable with death and may choose to not be present when their loved one dies. Many families are comforted to know that someone was with their loved one when they passed. Nurses and unlicensed assistive personnel can document at the bedside of those who are dying if there isn't family present.

Nothing to fear

My hope for all nurses caring for patients at end of life is to walk away at the end of their shift knowing they did their best to keep the patient comfortable and the family educated and supported. The great Maya Angelou once said: "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel." ■

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