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SHIFTING GEARS

From cure to comfort



DAVE COLLINS

Hundreds of thousands of patients die in ICUs each year, but few receive palliative care. Nurses play a central role in transitioning from aggressive treatment to comfort care.

It's 2:15 a.m. and the chart's been checked. There are no new orders. The sheets are clean, hiding the deterioration in progress.

As I gaze at the blood pressure monitor, the numbers flash in a strange rhythm: 76/40 ... 70/40 ... 72/40. Too low. Infusions hum while the balloon pump keeps time. Even the ventilator cycles seem to contribute to the macabre acoustics of technology.

Suddenly, the numbers on the monitor plummet, and I hear myself shouting for the code team.

Dramas like this are played out regularly in critical care settings nationwide. Far too often, patients approach the end of life only to be resuscitated when there's little hope of a meaningful recovery. ➤

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Today, more than 60% of deaths occur in hospitals,¹ and almost half of those patients have spent part or all of their last three days in the ICU.² Frequently, the controlled, high-tech environment interferes with what should be a profoundly personal experience for patient and family.

The care that dying patients receive in the ICU has gotten a great deal of attention in recent years as our rapidly aging population has helped to push end-of-life care onto the national stage.³ Yet only about a third of hospitals in the country offer palliative care

programs, and numerous studies show that significant gaps remain in the care of patients with serious, life-limiting conditions.⁴

Nurses play a central role in palliative care. However critical care nurses as well as physicians have little training in making the transition from aggressive, cure-oriented therapies to end-of-life care.⁵ Exploring your own feelings about death and coming to view it as a natural part of life will help you begin to understand that caring for dying patients (and their families) is an integral component of critical care nursing.⁶

Setting the stage for a shift in focus

Because so many patients die in ICUs, it's important to bring up the subject of end-of-life care when the patient is admitted to the unit. During your initial assessment, ask the patient—or the family of a patient who's unable to communicate—if he has an advance directive, even if an admitting clerk already raised the question. If the patient says No but expresses interest in having one, arrange for a hospital representative to meet with him as soon as possible.⁷

In discussing the treatment preferences of a patient with a life-threatening illness, include the family from the start, if the patient so desires. Ensure that they're kept abreast of changes in prognosis and also involved in any decision to cease aggressive treatment.

If the decision is made to stop aggressive treatment, you'll oversee pain management and comfort care and support family members. Although there's a perception that dying patients require little nursing care, providing palliative care can be a full-time job.⁸

Palliative care, as defined by the World Health Organization, is the active, total care of patients whose disease no longer responds to curative treatment.⁹ It's best approached by an interdisciplinary team, including physicians, social workers, clergy, and respiratory and physical therapists, as well as nurses.

Controlling pain and other symptoms and addressing psychological, social, and spiritual needs—while the patient is still aware—are paramount in palliative care. While the

Quick facts

- ▶ Nearly half of the patients who die in hospitals spend part or all of their last three days of life in critical care.
- ▶ Only about a third of hospitals in the country offer palliative care programs.
- ▶ Patients and families can benefit from being asked if there is anyone who needs to hear "Please forgive me," or "I love you."

Managing symptoms at the end of life

Symptom	Medication	Nursing care
Anxiety	lorazepam (Ativan), alprazolam (Xanax), phenobarbital, paroxetine (Paxil), sertraline (Zoloft)	Offer a caring touch; encourage family participation; provide music, massage, pet therapy, and aromatherapy.
Delirium	haloperidol (Haldol), methotrimeprazine (Levoprome)	Evaluate for drug reaction, liver failure, hypoxia, impaction, brain metastases, and electrolyte or glucose abnormalities. Reduce stimuli; increase quiet periods.
Dyspnea	oxygen, diuretics, bronchodilators, morphine, lorazepam, haloperidol, prednisone, nystatin (Mycostatin, Nilstat), fluconazole (Diflucan), antibiotics	Position for comfort; use a bedside fan.
Anorexia	metoclopramide (Reglan), prednisone, dexamethasone (Decadron)	Evaluate for pain, oral candidiasis, depression, constipation, dry mouth, gastritis, and chemotherapy or radiation therapy side effects (if applicable). Avoid procedures, treatments, or other stresses prior to meals.
Nausea/vomiting	ondansetron (Zofran), dexamethasone	Identify and reverse the cause. Practice good oral hygiene, and keep the environment clean.
Fatigue	dexamethasone, methylphenidate (Ritalin), amitriptyline (Elavil), sertraline	Assess for anemia, endocrine disorder, or infection. Implement rest/activity schedule to promote sleep.

Source: Ferrell, B. R., & Coyle, N. (Eds.). (2001). *Textbook of palliative nursing*. New York: Oxford University Press

actual interventions that define this type of care aren't only for patients who are dying, palliative care is based on the premise that individuals can be given the best life possible until they die.

Helping to make the pain go away

When asked to rank their basic needs, dying patients have said they wished to be free of pain, anxiety, and shortness of breath; to be kept clean; and to be touched.¹⁰ Inadequate pain assessment by both nurses and physicians is the primary barrier to keeping patients relatively pain-free.⁵ So it's particularly important to do everything you can to become thoroughly familiar with the patient's experience of pain.

The most reliable indicator is the patient's own words, but not all critically ill patients can tell you what hurts and how badly.¹¹ Ask a patient who can communicate what provokes the pain, whether

it is dull or sharp, whether it radiates, how severe it is, and whether or not it is continuous.

To assess the pain of an uncommunicative patient, look for rises in blood pressure or heart rate, and ask the family or close friends to help. Studies show that family members usually can tell if a patient is in pain, although they often underestimate the severity.¹²

You can also use a pain evaluation tool based on physical indicators. (You'll find one in "Taking the fifth [vital sign]" in the July issue of *RN*.)

At each shift, re-evaluate and document the effectiveness of pain medications and report grimaces and other nonverbal expressions of pain. As you would with any critical care patient, exercise a high level of suspicion about the presence of pain. It's important, too, to plan for analgesia before moving the patient; assess for anxiety and depression, which are associated with increased pain; and avoid undertreating pain

because of a fear of addiction.^{11,13}

When you are delivering end-of-life care, it is also essential that both the nurses and the patient's physician understand and adhere to the "principle of double effect." Administering opioids in the amount necessary to significantly decrease pain may have the unintended consequence of hastening death. Doing so is ethically sound—as long as the intent is to ease suffering.^{11,13} For more on the ethics of administering narcotics for pain relief, see page 28.

Treat the person, not just the illness

Caring for the whole person is a key concept in end-of-life care. One way to do that is to think about what are often referred to as the "domains" of a patient—meaning his physical, psychological, social, and spiritual needs. Assessing patients—and their families—using this approach will help you focus on quality of life rather than traditional prob-

lem-oriented care.

The physical domain encompasses the management of symptoms such as nausea and fatigue. (See the box on page 55 for suggested interventions.) It also includes comfort measures such as frequent repositioning, padding bony prominences, and scrupulous attention to skin care to prevent the development of pressure ulcers.

A good way to determine the patient's needs in the other domains is to ask questions designed to elicit his thoughts, feelings, hopes, and values. (You'll find a sampling of such questions in the box at right.)

Listening carefully and responding, even in small ways, may not only help the patient feel better, but also improve the family's perceptions about the quality of care in the last days. For example, allowing the family to remain by the bedside despite restrictions on visitation is a simple measure that demonstrates your desire to address both psychological and social needs. So, too, is having a family member participate in physical care, such as bathing, or letting a loved one lie in bed beside the patient.¹⁴

Helping families prepare for death

As the bedside nurse, you'll be the one who informs the doctor of changes in the patient's condition and tells the family when death is approaching. It's appropriate at this time to encourage family members to place photos and other sentimental objects in the patient's room to reminisce about his life. It is also a good time to follow through on the spiritual

Questions to ask your patient

Asking patients questions like the ones below can help you find out what's most important to them—a key part of meeting their physical, social, psychological, and spiritual needs.

- ▶ What do you know about your illness? Is there anything more you would like to know?
- ▶ If you were so sick that you could not speak, who would be able to talk with me about your care?
- ▶ How would you communicate with me nonverbally?
- ▶ What's most important to you at this point in your life?
- ▶ What are your most important relationships?
- ▶ What do you think is most important to your family?
- ▶ When you think about being very sick, what worries you the most?
- ▶ What brings you comfort and joy?
- ▶ Do any spiritual or religious practices bring you comfort? Can you describe them?
- ▶ How does your culture affect decisions about medical treatment?
- ▶ What are your customs and beliefs about birth, illness, and death?
- ▶ How can I help address these issues while I care for you and your family?

wishes of patients and families, such as arranging for a chaplain's visit.¹⁵

Most families struggle to know the meaning of changes they're noticing, such as more labored breathing. If you're not sure how much they want to be told, simply ask an open-ended question, such as, "Some people want to know what dying looks like. Others prefer not to know or want me to speak with some other member of the family about it. How do you feel?"

If the patient can communicate, encourage him to express his fears or tell you what's on his mind.

Handling patient and family questions can be challenging. Nursing education failed to prepare many of us for the final phases of illness. But it's impor-

tant for nurses, especially those in critical care, to be familiar with the signs of dying and comfortable in explaining the process.

About a week or two before death, this is what to look for:¹³

- ▶ Weakness and lethargy, increased sleeping or restlessness
- ▶ Increased dependence on caregivers
- ▶ The patient may begin talking about visits from dead relatives
- ▶ Progressive disorientation
- ▶ An increasingly short attention span or withdrawal from the family
- ▶ Decreased interest in food and fluids
- ▶ Difficulty swallowing
- ▶ Incontinence.

Two or three days before death, you may notice the following:¹³

- ▶ Decreased level of awareness

- ▶ Eyes glassy; pupils unfocused
- ▶ No interest in food or fluid
- ▶ Abnormal breathing patterns
- ▶ Blood pressure and pulse more difficult to obtain
- ▶ Unexpected surges of energy
- ▶ Progressive cooling and mottling of extremities.

The accumulation of mucus in a dying patient's large bronchi may cause the loud, noisy respirations known as the "death rattle," which is very distressing to family members. The secretions can be reduced with sublingual administration of anticholinergic agents such as hyoscyamine (Levsin, Anaspaz, others) or with a diuretic.¹⁶

Dying patients often have difficulty swallowing and may refuse to eat or drink. Reassure the family that anorexia is normal at the end of life and explain that hydration can actually increase discomfort by causing respiratory secretions and distress, increased gastrointestinal secretions, nausea, vomiting, edema, and ascites.

During this time, you may be able to involve the family in an activity described as "reconnection," a way for people to work through any lingering difficulties in their relationships.¹⁷ Ask both the patient and his family members: "Is there anyone who needs to hear, 'Please forgive me,' 'I forgive you,' 'Thank you,' 'I love you,' or 'Good-bye'?"¹⁸

The caring continues when the patient dies

When the patient dies, avoid abruptly abandoning the family. If the family wishes to see a member of the clergy, you should offer to notify the hospital chaplain or appropriate community religious leader. Allow the family to see the deceased in private and to

perform any religious or cultural customs they wish. For instance, in Eastern Orthodox religions, a person's arms are crossed after death, with the fingers set in the shape of a cross.¹⁶

Empathize with grieving family members by touching them gently, holding their hands, and hugging them if you think they would be receptive to it. Tell them about bereavement counselors and groups for people who have experienced the death of a loved one.¹⁶ And don't be afraid to grieve with them. As one intensive care nurse put it, "You are not lessened in the family's eyes if you shed tears with them. It validates the family's loss."¹⁴

Caring for patients at the end of life is something you will no doubt do with greater frequency as the baby-boomer population ages. To do it well, it's crucial to think of death as a normal and natural part of the human experience—and to find a way to talk comfortably about it. Within critical care nursing, we have the privilege of not only participating in the deeply personal experience of someone's death, but also in helping them to truly live until the final moment. **RN**

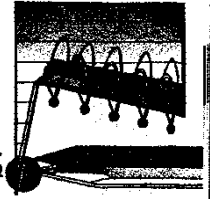
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Do you ask new critical care patients whether they have signed an advance directive to determine care at the end of life? Visit www.rnweb.com and vote in our poll.



Coping with grief

AFTER SOMEONE YOU LOVE dies, you may have feelings ranging from sadness to guilt to anger. You may feel this way even if you knew your loved one was going to die and thought you were ready for it. These strong, painful feelings are normal and may continue for a long time as you learn to cope. This guide will help you understand your feelings and deal with your grief.

What is grief?

Grief is the way you show the pain you're feeling. You may find yourself crying, having panic attacks, or feeling tired or depressed most of the time. You also may have nagging aches and pains, such as an upset stomach or headaches. You may not feel like eating or may have trouble sleeping. Grieving is hard on your body and soul, and it may make you prone to getting sick.

We each show grief in our own way, but there are some common feelings.

- A child's death may seem unfair to you because of the events the child will miss, her senseless suffer-

ing, and your own dreams that won't come true.

Many parents feel that the child's death was somehow their fault, no matter how untrue that is.

- A spouse's death can mean losing a lifetime of shared experiences. As the surviving spouse, you also may face a loss of income and major social changes, such as having to raise children alone, adjusting to single life, and perhaps going back to work.
- Any sudden death, such as from a car accident or heart attack, is hard to understand and accept. You may have trouble believing it really happened, which is sometimes called "being in denial."
- Death from suicide can leave survivors feeling guilty, angry, or ashamed. Going for counseling during the first weeks after a suicide can help you deal with these feelings.

How do I learn to live with grief?

These suggestions may help you cope with your pain and deal with the changes in your life.

Resources for the grieving

Check your local Yellow Pages under "social services" for support groups in your area. These national groups also may be helpful:

- The American Association of Retired Persons has a grief and loss resource area at <http://www.aarp.org/griefandloss>.
- Compassionate Friends is a support group for people who've lost a child. You can find a local chapter by contacting the organization at 1-877-969-0010 or <http://www.compassionatefriends.org>.
- Friends for Survival helps people who've lost family or friends to suicide. Contact 1-866-538-7366 or <http://www.friendsforsurvival.org>.
- GriefNet.org offers 47 e-mail support groups for children and adults working through many types of grief. Visit <http://www.griefnet.org>. GriefNet offers another Web site for bereaved children and parents: <http://www.kidsaid.com>.

- Seek out caring people. Spend time with family and friends who understand your feelings of loss. Join support groups for people who've had losses like yours.
- Don't be ashamed to talk about how you feel. This will help you work through your grief.
- Take care of your health. See your health care provider regularly, eat well, exercise, and get enough sleep. Don't rely on alcohol or drugs to dull the pain.
- Celebrate the happy times you had with your loved one and share those memories with others.
- Postpone major life changes, such as marrying, changing jobs, having a child, or moving to a new home. Give yourself time to adjust to your new life after the loss.
- Be patient with yourself. Don't expect to "get over it" quickly. Coping with a major loss and accepting your changed life can take a year or more.
- Reach out for help when you need it. Call a friend if you feel lonely or want to talk. If your grief seems like too much for you, ask a health care professional or your pastor or other trusted spiritual leader for help. ☺

Adapted with permission from *Coping with Loss—Bereavement and Grief*, National Mental Health Association, 2004, <http://nmha.org/infoctr/factsheets/42.cfm>.

This patient-education guide has been adapted for the 5th-grade level using the Flesch-Kincaid and SMOG formulas. It may be photocopied for clinical use or adapted to meet your facility's requirements. Selected references are available upon request. For more tips on writing education guides, see the first article in this series: "Writing Easy-to-Read Teaching Aids" (March 2002).

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