

Improving the Quality of End-of-Life Care

Making changes at every level.

By Rose Virani, MHA, RN,C, OCN, and Dalia Sofer

Dave Fulkerson was an active, healthy 22-year-old when he was struck by a car and sustained multiple injuries while jogging one day with his girlfriend, Sue Rundlett.

He was stabilized in the ED, then transferred to the ICU. Mr. Fulkerson's parents, who rushed over after hearing about the accident, and Ms. Rundlett were asked to stay in the waiting room. The patient's mother pleaded to see her son but was repeatedly told that "it would only be a short time" before she could do so. A half-hour later the physician informed them that because the injuries were so severe, Mr. Fulkerson needed assistance breathing. His parents consented to have their son intubated. It wasn't until three hours later that the three of them were allowed to see Mr. Fulkerson, who by this time was sedated and couldn't communicate. Over the next several hours, they were allowed to visit him for five minutes every two hours, only one at a time. Frustrated at not being able to spend more time with

her boyfriend, Ms. Rundlett left the hospital.

Later that day, the admitting clerk questioned Mr. Fulkerson's parents about their son's insurance coverage. They told the clerk that since he no longer lived with them, they were unsure but gave him the name of their son's employer. With no further news about his status, they fell asleep in the waiting room.

At 5 AM the staff nurse awakened them. The physician soon followed. Their son could not be saved, she told them. She said she was sorry. "There must be some hope if you put him on a breathing machine!" Mr. Fulkerson's mother pleaded. The doctor defensively insisted that she had done everything possible. The parents tried to call Ms. Rundlett

Bigger Than Each Other, by Deidre Scherer, fabric and thread, 36" × 30", 2000; photo by Jeff Baird.

Through a hospice in Vermont, the artist met a patient with chronic obstructive pulmonary disease. Scherer depicted the patient and her husband discussing her illness. "She leaned against his chest. They discussed a DNR order and her funeral, which brought relief for her and many new realizations for him."

For more on the artist and her work, go to www.dscherer.com.

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Palliative Nursing



Making the time spent at the end of life precious—not merely tolerable—is one goal of end-of-life care, as stated by the American Geriatrics Society.

but couldn't reach her. Mr. Fulkerson died shortly thereafter.

After saying goodbye to their son, the parents ran into the admitting clerk, who, unaware that their son had already died, told them that he may have to be transferred to another facility because the hospital was not a provider of his insurance carrier. The mother, who had contained her emotions until this point, lashed out at him. "What kind of hospital is this? My son just died!" she cried. Embarrassed, the admitting clerk walked away.

They left the hospital, carrying with them their son's belongings—the clothes he'd been wearing the day before, his wallet, and his chronographic watch, which just a day earlier he'd been using to monitor his afternoon jog.

Mr. Fulkerson's care was marred by many mishaps, not the least of which was lack of communication among hospital staff and between the health care team and the family. Not providing the patient's parents and girlfriend adequate time with him during his final hours and not offering social services, pastoral care, or bereavement resources to comfort them, were all shortcomings in care. Thus the abrupt death of a young man was made even more painful by a poorly orchestrated system.

Poor communication is not the only obstacle to a peaceful death. Some patients are overtreated, receiving aggressive care until their last breath.

Others are undertreated, so much so that their final moments are steeped in physical pain. Still others receive conflicting advice from doctors and nurses on the best course of action, leaving them confused and unprepared for death.

Perhaps of all the issues that health care workers face, death is the most challenging. After all, it can neither be tested nor measured. Since no one among the living has experienced death, one cannot turn to experts for advice. Often, health care workers have fears of dying and may act according to them; they may also regard death as a sign of failure rather than the natural culmination of life. Family members play a role too—bringing into the picture their distress, anger, and grief.

While no one can define a good death in absolute terms, it's possible to improve the quality of care during the final days of a patient's life. Nurses, who often spend the most time with a patient and his family, can best identify and help amend the shortcomings of end-of-life care.

A MASSIVE JIGSAW PUZZLE

A peaceful death doesn't depend entirely on one person. The way a person's final days will be spent depends on the patient, the family, physicians, nurses, the policies of the hospital or hospice (if the patient isn't at home), and insurance providers. On a more distant but equally important level, state and federal laws regarding such issues as advance directives, the curricula in nursing and medical schools (which determine clinicians' awareness of end-of-life care), and the efforts of researchers, community groups, medical societies, government organizations, and charitable foundations affect the quality of end-of-life care. All of these factors may conspire to make what should be the most intimate period of a person's life—when one accepts the reality of leaving this world—the coldest and most impersonal.

According to a report by the Committee on Care at the End of Life at the Institute of Medicine, called *Approaching Death: Improving Care at the End of Life*, the result of having a multitude of players is that no one person or entity is held responsible for the quality of the care the dying receive.¹ And if no systems exist to measure outcomes and identify problems, even those who believe they are responsible—palliative specialists, hospice personnel, ethics consultants, chaplains, and others—may not always know whether they are fulfilling their responsibilities. Nurses may have the best intentions, but they alone cannot ensure a peaceful death for patients. Care should therefore be improved at all levels—

governmental, institutional, and individual—and nurses' involvement at all of these levels is essential.

DEFINING HIGH-QUALITY END-OF-LIFE CARE

Many researchers and organizations have conducted surveys and hearings to understand what factors contribute to the quality of care at the end of life. In 1996 the American Geriatrics Society introduced a list of nine such factors in a report called *Measuring Quality of Care at the End of Life: A Statement of Principles*.² While the report targets the elderly, it applies to all age groups and has been endorsed by more than 30 organizations, including the American Association of Critical-Care Nurses, the American Cancer Society, the American Pain Society, and the Oncology Nursing Society. It recommends attending to the following:

- the alleviation of physical and emotional symptoms
- the support of function and autonomy to help the patient maintain his dignity
- advance planning to ensure that decisions reflect the patient's preferences
- guarding against inappropriate aggressive care near death
- making the time spent at the end of life precious—not merely tolerable—to the patient and family
- ensuring that the quality of the patient's life is good despite declining physical health
- working to minimize the financial burdens that care places on the family
- educating patients in the length of time insurance companies cover treatment of a terminal illness
- helping the family with bereavement

Americans for Better Care of the Dying also has compiled a list of measures (see *Making Promises*, at right).

MEDIOCRE REPORT CARD

Many organizations and researchers are working to assess where end-of-life care falls short. The Institute of Medicine has identified four major areas¹:

1. the overuse of care, such as unwanted treatments or hospitalizations
2. the underuse of care, such as a failure to assess and treat pain, late referral for hospice care, or premature hospital discharge
3. poor technical performance, such as errors in surgical technique or miscalculation of medication dosages for pain or other symptoms
4. poor interpersonal performance, which includes inept communication of difficult news

Last Acts, a campaign created in 1996 by the Robert Wood Johnson Foundation to improve care

Making Promises

What to say to patients and families.

- You will have the best medical and nursing treatment, aiming to prevent exacerbation, improve function and survival, and ensure comfort.
- You should not have to endure overwhelming pain, shortness of breath, or other symptoms, which will be anticipated and prevented whenever possible, evaluated and addressed promptly, and controlled effectively. Severe symptoms—such as shortness of breath—will be treated as emergencies. Sedation will be used when necessary to relieve intractable symptoms near the end of life.
- You will receive continuous, comprehensive, coordinated care, and you and your family can count on timely response to your needs. Transitions between services, settings, and personnel should be limited and smooth.
- You and your family will be prepared for everything that is likely to happen in the course of your illness.
- Your wishes will be sought, respected, and followed whenever possible. You will never receive treatments you refuse.
- We will help you and your family to consider your personal and financial resources, and we will respect your choices about the use of them. You will be informed of services available in your community and the costs of these services. Family caregivers' concerns will be discussed and addressed. Respite care and home care will be available when appropriate.
- We will do all we can to see that you and your family have the opportunity to make the best of every day. You are treated as a person, not a disease, and what is important to you is important to the care team. Families are supported before, during, and after a patient's death.

Source: Adapted with permission from Americans for Better Care of the Dying. *Action Guides*. 2001. <http://www.abcd-caring.org/tools/actionguides.htm>. (For additional information, read Lynn J, et al. *Improving care for the end of life: A sourcebook for health care managers and clinicians*. New York: Oxford University Press; 2000.)

near the end of life, rated the 50 states and the District of Columbia on eight criteria: state advance directive policies, the location of death (in relation to patients' wishes), hospice use, hospital end-of-life care services, care in ICUs at the end of life, pain among nursing home residents, state pain-control policies, and the number of palliative care-certified physicians and nurses.³ Its report, *Means to a Better End: A Report on Dying in America Today*, revealed overwhelmingly disappointing results. For example, despite the enactment of the Patient Self-Determination Act in 1991, requiring all health care facilities that receive Medicare or Medicaid reimbursements to inform patients of their right to choose the treatments they receive and to prepare advance directives, 30 states scored fewer than three

points (out of a possible five) on their advance directives efforts. In addition, while studies have shown that 70% of patients wish to die at home, in 43 states fewer than 30% of people did so; the District of Columbia came in last, at fewer than 15%. The report also found that in 45 states fewer than 60% of hospitals provide pain management programs and that in 39 states fewer than 20% of them offer palliative care services.

IMPROVING CARE OF THE DYING

A peaceful death can only be achieved through a well-orchestrated system of care that includes individuals, health care workers, hospitals, policymakers, and medical and community organizations. Change must therefore occur not only on an individual level, but on a systems level as well.

Federal, state, and community levels. Thirty states have created end-of-life organizations, designed to assess care given and to make necessary changes. The California Coalition for Compassionate Care, for example, has set out to provide end-of-life care guidelines for skilled nursing facilities, as well as advance care planning tools in English and Spanish; the Florida Partnership for End-of-Life Care has established the state's first pain management training program for pharmacists, a do-not-resuscitate-order demonstration project, and an end-of-life care education program for emergency personnel; and the Maine Center for End-of-Life Care has established a hospice-palliative care rotation for second-year medical students and an interfaith manual on end-of-life care.

You can find out whether your state has a task force or commission on end-of-life care by accessing the Last Acts report (www.lastacts.org/files/misc/meansfull.pdf) and going to the chapter "Momentum for Change." If your state isn't on the list, or if upon reviewing its initiatives you don't believe they are sufficient, consider contacting your local (and federal) policymakers. Americans for Better Care of the Dying has provided a series of recommendations for policymakers. They include⁴

- tailoring policies to people who have a terminal illness in addition to those with a prognosis of less than six months.
- providing coverage of prescription drugs essential for symptom relief.
- changing Medicare regulations that limit coverage to treatments that "maintain or improve function" and initiating statutes supporting treatments that slow down the loss of function or ease suffering.

- changing Medicare payment and regulations to ensure that those nearing death receive continuous care regardless of where they spend their final months—at the hospital, at home, or in a nursing home.
- requiring an annual report on the status of end-of-life care from the secretary of Health and Human Services, in collaboration with the surgeon general.
- offering insurance coverage, employment security or help with reemployment, coverage for respite help, partial payment for family care when the patient would otherwise need paid care, and tax breaks.

Hundreds of medical, nursing, and community organizations also have developed end-of-life care programs. For example, the Life's End Institute: Missoula Demonstration Project, a community project based in Missoula, Montana, has established an online service (www.choicesbank.org) that allows patients to store their advance directives privately and free of charge in an Internet database that can be accessed anytime and anywhere. Another example is MediCaring (www.medicaring.org), a program developed as a national demonstration project by the Center to Improve Care of the Dying, which blends palliative care with medical and disease management for seriously ill patients, particularly those with congestive heart failure and chronic obstructive pulmonary disease in the final two to three years of their lives. Unlike the Medicare hospice benefit, which is limited to those with a life expectancy of six months or less, MediCaring is designed for people with a serious chronic illness that will cause death, even when it takes longer. Because MediCaring is expected to decrease costs by diminishing the use of acute care interventions, it's intended to become part of current Medicare funding.

Promoting Excellence in End-of-Life Care, a program of the Robert Wood Johnson Foundation, has provided \$15 million in grants and technical support to programs designed to change the experience of dying; 23 nationwide projects are under way. The Center for Gerontologic Nursing Sciences at the University of Pennsylvania School of Nursing in Philadelphia, in collaboration with Genesis Elder Care, the nation's third largest long-term care provider, is evaluating a palliative care program to enhance the care of nursing home residents at the end of life; a University of Chicago clinical research team is implementing a two-part program to improve end-of-life care in patients with dementia; and the Volunteers of America, the Virginia-based organiza-

An Example of Quality Improvement

How RNs might improve the quality of pain control on their units.

Steps to Quality Assurance & Improvement	Example
Establish a CQI committee willing to improve end-of-life care and measure outcomes.	Medical-surgical RNs have recognized uncontrolled pain in patients admitted with terminal cancer. The RNs contact their hospital's CQI committee to propose a unit-based project.
Collect data to encourage changes in practice (for example, in staff members' attitudes).	The unit CQI committee collects pain control data, tests staff knowledge and patient satisfaction, and examines patient charts to assess pain and its treatment.
Review existing outcome measures and consider use in one's own setting.	Audit tools are used from the City of Hope Pain/Palliative Care Resource Center: http://prc.coh.org .
Begin collecting data on a small scale. Develop a feasible plan with repeated measurement. Ensure that something already proven effective is in fact being delivered as intended (such as use of opioids for pain control).	The staff assesses 10 patients on admission in the next 3 months using the above measures. They complete chart audits at discharge or death.
Consider other methods of data collection (patient satisfaction surveys).	Since many patients die during hospitalization, the RNs collaborate with hospital social workers to interview surviving family members.
Gather results and determine if change is needed. Involve staff in problem solving.	The CQI committee hosts a meeting to review the audit results. The pain team, social workers, and local hospice nurses are invited.
Implement institutional change (if needed).	Based on the audit, the CQI committee recommends revising protocols for opioid infusion and titration, implementing a bowel protocol, and using a patient education video on pain. A liaison with hospice is arranged.

CQI = continuous quality improvement

Adapted with permission from Solomon M. Institutional accountability in end-of-life care: organizational leadership, measurement, and consumer demand. In: Solomon M, et al., editors. *Innovations in end-of-life care: practical strategies & international perspectives*. Larchmont, NY: Mary Ann Liebert, Inc.; 2001. p. 137-42.

tion that has provided support to prisoners, parolees, and their families for more than 100 years, is addressing the end-of-life care provided to prisoners. To view all of the grantees and their projects, visit www.promotingexcellence.org/navigate/grantees.html.

In February 2000 the American Association of Colleges of Nursing and the City of Hope National Medical Center in Duarte, California, launched the End-of-Life Nursing Education Consortium (ELNEC), a national education program for nurses designed to improve end-of-life care. The project has so far trained more than 1,300 nurse educators from all 50 states; the educators have in turn shared their expertise with nursing students and colleagues. To find out more about ELNEC, visit www.aacn.nche.edu/ELNEC/about.htm.

Institutional level. Many clinicians have estab-

lished initiatives to improve end-of-life care in their own institutions. At the Detroit Medical Center, a level I trauma hospital where more than 30% of hospital beds are dedicated to critical care, a palliative care program consists of a comprehensive supportive care team (CSCT) led by Margaret Campbell, an advanced practice nurse, in collaboration with a staff physician. Other hospital staff members are called upon as needed. The team shares accountability, decision making, and patient management.

Patients who were not expected to survive hospitalization were referred to the CSCT, which evaluated each patient by reviewing medical records and discussing with the patient or a surrogate the decision to move to palliative care. If consensus was reached among the CSCT, the referring physician, and the patient or a family member, the CSCT

RESOURCES

Americans for Better Care of the Dying	www.abcd-caring.org
Center to Advance Palliative Care . . .	www.capcmssm.org
Center to Improve Care of the Dying	www.gwu.edu/~cicd
Community-State Partnerships to Improve End-of-Life Care	www.midbio.org
Hospice and Palliative Nurses Association	www.hpna.org
Innovations in End-of-Life Care	www.edc.org/lastacts
Last Acts	www.lastacts.org
National Hospice and Palliative Care Organization	www.nhpco.org
Partnership for Caring	www.partnershipforcaring.org
Supportive Care of the Dying	www.careofdying.org

accepted responsibility for the patient and developed a comprehensive plan, taking into account the patient's advance directives, wishes regarding comfort, and psychological and spiritual needs. Once the patient or his surrogate approved the plan, the advanced practice nurse implemented it.

While patients' satisfaction couldn't be measured because of their decreased level of consciousness, family members reported high levels of satisfaction with patient care and the support they received. One family even expressed its appreciation to the staff in the patient's newspaper obituary: "The family wishes to thank . . . for their kind, caring, highly skilled, dedicated help during a very difficult time."⁵

Marilyn Bookbinder, director of nursing at the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center in New York City, is an expert in quality improvement. At her hospital she developed "Palliative Care for Advanced Disease" (PCAD), a guideline for the interdisciplinary management of hospitalized dying patients. PCAD consists of three components:

- a list of suggested treatments, along with ways to create an interdisciplinary plan of care for dying patients

- an MD order sheet—a tool used for controlling patients' symptoms; the reverse side of the form includes medications that may be considered for treating pain and 13 additional symptoms dying patients frequently experience
- the daily patient care flow sheet—a tool that nurses use to document daily assessments and interventions

On its Web site, www.stoppain.org, the Department of Pain Medicine and Palliative Care at Beth Israel indicates how the PCAD pathway should be used:

Step 1: Identification of a patient likely to die within minutes or days; any staff member may suggest a patient for the PCAD pathway

Step 2: Interdisciplinary assessment of the patient and discussion with the primary provider

Step 3: Provider clarification of goals of care with the patient and family

Step 4: Implementation. The primary provider orders the PCAD pathway using a specific order sheet and rewrites the orders for the patient; nurses complete the demographic information on the PCAD pathway forms and initiate a flowsheet of daily care

Step 5: Discharge. The patient is discharged or dies on the unit; a family bereavement policy is initiated (for example, a condolence card is sent), as is a staff debriefing session

To learn more about the PCAD pathway, visit www.stoppain.org/services_staff/pcad1.html. To read an extensive interview with Bookbinder and the pathway she created, visit www2.edc.org/lastacts/archives/archivesJuly01/bbfeatureinn.asp.

In a study published in the *American Journal of Critical Care*, nurses identified the obstacles that stand in the way of providing high-quality end-of-life care and the measures that would most improve it.⁶ The most challenging obstacles had to do with the families of the dying patient and included "family and friends who continually call the nurse rather than the designated family member," "family members not understanding what the phrase 'life-saving measures' really means," "family not accepting a poor prognosis," and "providing life-saving measures at families' request, even though patient had signed an advance directive requesting no such care." Other obstacles included "physicians who are overly optimistic about patient surviving," "giving painful treatments to a dying patient," and "not enough time to provide end-of-life care because nurse is consumed with lifesaving activities."

The measures nurses identified as most helpful

included “all physicians agreeing about direction of care,” “providing a peaceful, dignified bedside scene for family after patient’s death,” “having one family member as designated contact for all information,” and “having enough time to prepare family for patient’s death.” The researchers point out that although nurses ranked families’ continuous phone calls as the greatest obstacle, they didn’t necessarily consider the families an obstacle; phone calls are disruptive because they take the nurse away from the bedside and diminish her time with patients. In fact, the measures nurses ranked as most helpful all had to do with increasing support for families.

As a nurse, you can begin to improve end-of-life care in your institution by reviewing the medical charts of palliative care cases. Once you identify shortcomings, collaborate with the quality improvement department of your institution on end-of-life care. For example, an ICU may want to revise family visitation policies for patients who aren’t expected to survive.⁶ Other helpful measures may include ensuring the availability of clinical protocols for symptoms such as pain, dyspnea, and agitation; establishing relationships with the social services department or with pain and symptom management teams; communicating with the patient and his family about the patient’s approaching death; ensuring better use of advance directives; and providing bereavement services for the family.

Dozens of assessment tools are available. The City of Hope Pain/Palliative Care Resource Center (<http://prc.coh.org>) in Duarte, California, offers a list of them. In addition, you may seek the assistance of external organizations to design your project. The Center for Palliative Care Studies has worked with nearly 100 health care organizations to implement quality-improvement projects in end-of-life care. It provides intensive quality improvement educational sessions, follow-up site visits, phone and e-mail consultation, and proposal writing for project funding. To learn more about how your organization can work with the center, visit www.medicaring.org or send an e-mail to Sarah Myers at info@medicaring.org.

Individual level. Day-to-day measures are perhaps the most helpful and immediate ways to improve the quality of care. Use the following list (courtesy of Joanne Lynn, MD, president of Americans for Better Care of the Dying)^{4,7}:

- Ask yourself as you see patients, “Would I be surprised if this patient died this year?” If you believe the answer is no, ask the patient, “What do you hope for, as you live with this condition?”

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to make what should
be the most intimate
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“What do you fear?” “If you were to die soon, what would be left undone in your life?” “How are things going for you and your family?” Use the answers to help develop a care plan that reflects the patient’s concerns.

- If you aren’t sure how to approach a patient about advance directives, ask, “If at some point you can’t speak for yourself, who should speak for you about health care matters?” “Does this person know about this responsibility?” “Does he or she know what you want?” “What *would* you want?” “Have you written this down?” If so, ask for a copy and add it to the medical record.
- Recognize your own attitudes and feelings about death.
- Respect the patient’s views and wishes during end-of-life care.
- Collaborate with interdisciplinary team members.
- Use scientifically based standardized tools to assess symptoms such as pain, dyspnea, constipation, anxiety, fatigue, nausea, vomiting, and altered cognition.
- Discuss the exacerbation of pain and other symptoms with the patient and his family. Inform them of the measures that can be taken to alleviate these, and make plans together.

- Very sick people are often most comfortable at home or in a nursing home. Identify programs that provide home care and inform the patient and his family about these or refer them to a social worker.
- Except in hospice, most families never hear from clinicians after a loved one's death. Make a follow-up phone call to or visit the family, answer questions, and affirm the value of the patient's life. At the very least, send a card.
- Never tell a patient, "There's nothing more to be done" or "Do you want everything possible done to save your life?" Talk instead about the life yet to be lived, and what can be done to make it better (and what might make it worse).

Clinicians cannot reverse death, but they can make dying more peaceful for patients and families. ▼



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CE 1.5 HOURS

Continuing Education

GENERAL PURPOSE: To provide professional registered nurses with information on ways to improve the quality of end-of-life care.

LEARNING OBJECTIVES: After reading this article and taking the test on the next page, you will be able to:

- Outline various reports, resources, and organizations that currently influence end-of-life care.
- List recommendations that have been made to improve end-of-life care.
- Discuss the implications for nurses who provide end-of-life care.

To earn continuing education (CE) credit, follow these instructions:

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