

# REALIGNING PERSPECTIVES ON END-OF-LIFE CARE

By Karen J. Stanley, RN, MSN, AOCN®, FAAN



ILLUSTRATION BY DAVE PERILLO

## Accommodating Patients' Wishes Without Compromising the Health Care Team's Values Can Be Daunting

Most patients facing the end of life express the desire to die at home among family and friends. However, unavoidable realities often steer them to acute care settings where they spend their final days.

Providing morally and ethically appropriate care in accordance with patients' wishes without compromising the ICU health care team's values can be daunting. Dilemmas occur frequently as patients, families and health care providers struggle with decision-making. Developing a greater sense of collaborative understanding among these parties will ensure patients the best in symptom management and the kind of care that reflects their personal wishes at the end of life.

However, during emergent circumstances in the ICU, practitioners have little time to form relationships with patients and families that foster discussions about end-of-life options. When possible, it's far better to talk with patients about end-of-life care before they arrive at the ICU, according to Craig Arakaki, MD, pulmonary intensivist at the Kaiser Permanente Medical Center in Fontana, Calif.

"If you start talking to patients about end-of-life care when they arrive at the ICU, especially in an HMO setting, many of them may think you're trying to cut costs and save money," he said. "They may feel uncomfortable, threatened and reluctant to engage in the conversation. Or they may ask for more care because they fear you'll withhold care."

The abundance of high-technology equipment in an ICU may appear formidable and frightening to patients, which reinforces an unwarranted notion that the patient is there for

intensive care only and lacks the knowledge to contribute to the decision-making process. As a result, patients may not voice personal concerns and may defer almost totally to the health care team. They also may lack the physical, mental and emotional wherewithal to take the initiative to ask questions.

Practitioners can help patients express their wishes. "I avoid asking patients direct yes-or-no questions," Dr. Arakaki said. "Instead, I ask them about their values and wishes, what they think about their disease and their care. This helps me to get a feel for what patients want without them feeling pressured."

This approach also helps patients to experience a greater sense of control over their situations. "Many people think that if you talk with patients about dying, the patients will give up, but the

opposite is often true," Dr. Arakaki said. "Patients are stronger than we think. Providing them with more of a say about what goes on enables them to dictate what happens to them, gives them more control, and they feel less helpless."

#### CRISIS POINT

In time, a crisis point arises when the disease-focused model of health care no longer provides viable options to a patient in an intensive care situation. At that point, a patient may require only palliative or comfort care. While the time for intensive intervention has passed, decisions may not yet have been made about the level or intensity of care a patient desires. At this stage, a patient who has moved rapidly through the illness continuum and has exhausted treatment alternatives may be unprepared for the quick decision-making required under these circumstances.

## FEWER PATIENTS CAN EXPECT TO DIE AT HOME

**O**ur culture has lost the ethic of families caring for dying relatives in the home. "From the 1950s on, people began going into hospitals more often because of the life-saving technology there," said Mark Mangus, BSRC, RPFT, RRT, pulmonary rehabilitation coordinator at the Christus Santa Rosa Medical Center in San Antonio. "Today, few people know how natural it is to die at home, and the end-of-life paradigm is built on dying in a high-tech hospital environment."

A patient dying at home may experience respiratory difficulty but may be adequately medicated so that he or she isn't exhibiting discomfort, he said. Having family around can further mitigate suffering. The patient is able to die under his or her own volition without all the technology and impersonal atmosphere of an ICU.

"In an ICU with all the tools to keep patients alive, the temptation to avoid is to keep patients alive at all costs, especially when it's time for them to die," he said.

However, for many patients, dying at home is difficult and requires extensive planning to accommodate their physical, mental and emotional needs. There may be no family caregivers to provide care 24 hours a day. Aging spouses may lack the physical and emotional strength for the task. Families may be geographically

disparate, and married sons and daughters raising families on two incomes may have little time to care for dying parents.

To complicate matters, the nature of Medicare reimbursements for hospice care may delay transfer of critically ill patients from hospital to home hospice programs. To enroll a Medicare-eligible patient in a hospice program, a physician must sign a document attesting that a patient is expected to die within six months. Knowing when patients will die is often impossible, because their conditions may cause them to linger well beyond the ICU staff's anticipations.

"A patient with COPD may live for 20 years, and then get an infection and die soon after, or be sustained for yet longer, even years on a ventilator," Mangus said. "A patient ravaged by chronic disease and weak to the point where death is imminent may last for days, even with a very low cardiac ejection fraction and ultra-low hemoglobin count." No wonder that physicians often are reluctant to refer patients to a hospice.

Also, patients with terminal illnesses who aren't Medicare eligible and who lack hospice coverage in their health care benefit plans may find themselves in the acute-care setting during their final days. ■

—Karen Stanley, RN, MSN, AOCN®, FAAN

It's often difficult to know exactly when this crisis point occurs, but it's important to resist pushing one's own philosophical viewpoint on patients, whether that's for aggressive care or palliative care, Dr. Arakaki said.

"Sometimes, you may not be able to cure an underlying condition, but you may be able to improve a patient's quality of life for another couple of weeks, a month or some time, by providing critical-care treatment," he said.

Try to get a clear idea of where patients are with their disease and whether they want aggressive treatment or comfort care. "Rather than rushing to judgment, I explain their options and allow them to reach whatever decisions they need to make about their care. Some patients may want aggressive treatment, and others may want palliative care. But the critical focus is on what the patient wants, not on what families or what I want."

Families may find it difficult to make the actual shift from aggressive care to palliative care, but if given some time and patience by the ICU staff, many families do make the shift of their own accord and arrive at the same mindset as the staff, said Susan Hedlund, LCSW, clinical manager of social work and breast cancer counselor at Oregon Health Sciences University in Portland, Ore.

"A patient may arrive at the ICU after suffering a catastrophic stroke," she said. "During the first 48 hours, family members are devastated and may want everything done. They may sit by the bed day in and day out. But if the patient truly needs comfort care rather than aggressive treatment, many families come to realize this on their own."

The ICU setting may make it difficult for a patient to transition to palliative care by keeping alive the buried hope of survival and delaying the needed settling of affairs, bidding goodbye to family and friends, and preparing oneself to die. With its emphasis on saving life, the ICU environment also may lull a patient at the end of life into believing that death may not be inevitable and that some possibility, however small, exists that he or she will live.

To assist in the transition, a patient needs palliative care professionals educated, trained and experienced in addressing the unique circumstances patients face at this stage. Palliative care professionals can facilitate patient and family decision-making and assist in determining when a patient is best served by palliative versus curative

care. Legitimizing and involving these professionals in intensive care settings can help offset the anxieties and fears of patients and families.

#### ADVANCE DIRECTIVES

Patients in ICU settings nearing the end of life need assistance with the completion of a health care directive. They need realistic explanations about prognosis, treatment options, risks and benefits, and granting permission to stop aggressive care if so desired. They also need literature to read, if they haven't effectively addressed these issues.

"It's imperative to get everyone in the same room talking with one another, particularly when more than one specialist is involved in a patient's care," Hedlund said. "If the physicians fail to reach a consensus, staff and families get caught in the middle as they try to work out a course of action."

A periodic care conference gives families a guideline of what to look for, reassures them that the ICU staff will reconvene with them as conditions change, and keeps them from getting lost in the process.

Federal law requires health care facilities that receive Medicare or Medicaid funding provide patients with information about an advance directive during admission. In most cases, patients need detailed assistance in preparing this document. Without this help, a patient may execute advance health care directives not explicit enough to be of any practical value.

"Someone in a coma with no chance to survive may have directed not to be kept alive, but it may be difficult to know what 'no chance' means," Dr. Arakaki said. "Should a 5 percent or 10 percent chance of survival override the no chance? In any event, whatever the written advance directive states, there is no substitute for actual discussion with the patient on his or her values and wishes in regards to end-of-life care."

The advance health care directive should be based on a patient's wishes and values. Otherwise, family members may make decisions based on their sense of impending loss and may ignore or delay responding to a patient's wishes. Patients should know that an advance directive takes effect only if they're no longer able to speak for themselves. Until then, they can change or revoke the health care directive, but the health care team should be informed in order to document the changes in the chart or place a copy of the revised document in an appropriate place.

The directive should appoint someone as the

agent, should the patient no longer be able to speak for him or herself. The directive also may name other people to act on behalf of the patient and rule out people whom the patient wishes to exclude from involvement.

The agent is empowered to make health care decisions for the patient according to the document's directives that define the agent's scope of authority. A patient's granting durable power of attorney for health care to another requires that informed discussion with the agent regarding health care choices takes place and that the agent has a copy of the health care directive in hand.

This process enables the patient to live and die as he or she wishes and spares family members the agony of making on-the-spot life-and-death decisions they may be ill-prepared to make. Prehospitalization preparation of a health care directive provides assurance to family members that discussion has occurred and decisions have been made, enables them to speak for their loved one with a sense of confidence, and spares them agonizing self-recriminations after a family member dies.

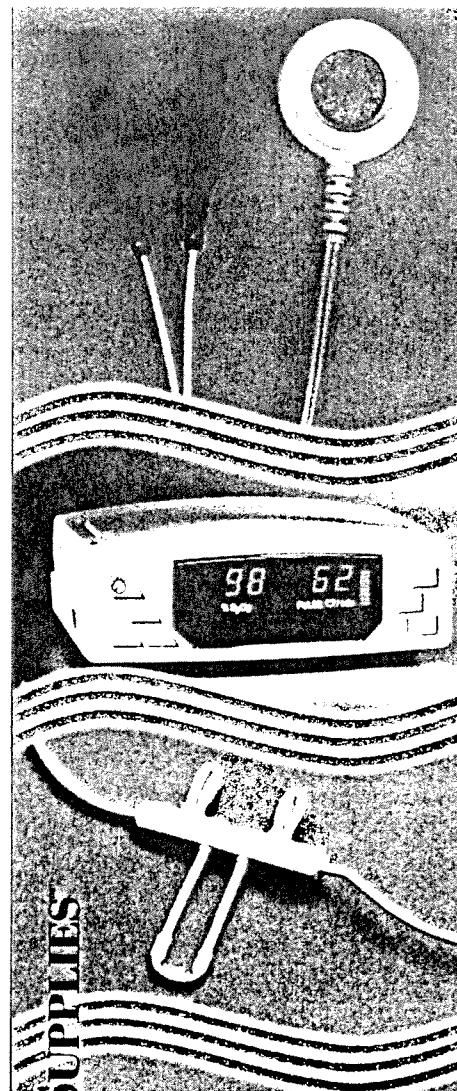
#### CONCLUSION

Patients cared for under the palliative model should receive excellent symptom management, pain control and comfort measures with attention paid to their and their families' psychosocial needs. In addition to developing policies about triaging patients to more appropriate care settings, hospitals need to develop ways to deliver end-of-life care in the intensive care setting. Structuring broadly multidisciplinary ICU health care teams is a good place to start. These teams can include chaplains, social workers, psychologists and palliative care experts who provide palliative-care input that enhances decision-making.

An openness to the realities of the health care continuum — from illness onset through worsening intensity to end of life — can realign the intensive care team's perspective on the most appropriate care. When this occurs, health care providers and patients will benefit from the very best medical care in a caring environment. Then, the anguish of prolonging death could become an issue of the past.

*Stanley is a nurse consultant for palliative care and past member of the board of directors of the Oncology Nursing Society.*

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