

# New Paths In End-of-Life Care

**D**eath and dying loom like an “uncharted continent” in contemporary American culture, said Joanne Lynn, MD, an organizer of the Innovators in End-of-Life Care National Conference, held in March in Washington, DC. “Those of us who work with the dying are like cartographers of the early 1500s trying to sketch America,” Lynn continued. “On one hand, that’s a daunting thought. But isn’t it exciting to be exploring a new world?”

Indeed, a sense of adventure emanated from the 120 physicians, nurses, hospice workers, healthcare administrators, and others who attended the conference. One indication of this was the care most speakers took to use only basic English—as if they feared that the professional jargon normally tossed around in such meetings would prevent participants from understanding each other.

“What should we call ourselves?” asked Lynn, director of George Washington University’s Center to Improve Care of the Dying. “Our interests are essentially the same, though we come from a variety of disciplines. We need to invent a term, something other than ‘people-who-provide-care-at-the-end-of-life,’ because that’s too awkward. Our field is so new that we don’t yet have a name for it.”

## A RENEWED INTEREST IN PALLIATIVE CARE

Dying is *terra incognita* today because, Lynn said, healthcare in the United States remains based on the myth that everyone will have a long, healthy life—and then die suddenly. “That was true in 1900, when the median age for death was 46,” she said. “But it’s not true now, when the median age for death is 80 and most deaths—typically from cancer, congestive heart failure, or chronic obstructive lung disease—are long and slow. The trouble is that, as a culture, we have almost no stories about how people die slowly.”

Partly because our culture has few such stories—and because, in the stories we *do* have, people die so painfully and with so little dignity—the



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average person finds the process increasingly terrifying, Lynn said.

That fear is one reason behind the recent surge of interest in palliative care, according to Sylvia McSkimming, PhD, executive director of Supportive Care of the Dying: A Coalition for Compassionate Care (SCD:CCC).<sup>1</sup> McSkimming explained that the coalition, based in Portland, OR, was formed in 1994 after Oregon’s voters approved a referendum measure decriminalizing assisted suicide. SCD:CCC, whose 12 members are Catholic healthcare organizations (including the Catholic Health Association), hopes to alleviate fear of dying through improvements in end-of-life care, McSkimming said.<sup>2</sup>

Lynn said that another cause of renewed interest in palliative care was the 1989-1994 Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). The study, funded by the Robert Wood Johnson Foundation, collected data on thousands of very ill hospital patients, identified problems with the care they received, and tried to rectify those problems. The attempt to correct problems failed, Lynn said, but SUPPORT nevertheless produced invaluable new pieces of knowledge, including these items:<sup>3</sup>

- More than 50 percent of the study’s patients were reported to be in substantial pain.
- Most of the patients who died spent their last days in an intensive care unit on the ventilator, unable to communicate with family or friends.
- Clinicians paid little attention to advance directives.
- The patients and their families often seemed “adrift and confused” about the illness and the care appropriate for it.

“Maybe the main thing the study revealed is that it’s very difficult to have a ‘good death’ in today’s healthcare system,” said Lynn, who was one of SUPPORT’s directors. “Given that dying will eventually happen to every one of us, we need to be asking: What would a successful death look like?”

## TOWARD A "SUCCESSFUL DEATH"

A partial answer to that question may be emerging from Missoula, MT, a mid-sized city of 85,000 where Ira Byock, MD, is principal investigator of the Missoula Demonstration Project, which he described as a "long-term, community-wide endeavor to study and transform the culture of dying."

Byock said the project was launched in 1996 with 30 focus groups in which area residents discussed experiences with the deaths of loved ones and their own hopes and fears concerning end-of-life care. The project's investigators are currently:

- Studying the medical charts of all city residents who died in 1997 to see what kind of end-of-life care they received
- Studying bereavement in 60 local families
- Developing a "pain scale" to be used in local hospitals and encouraging physicians to routinely ask patients about the extent of their pain

A "successful death," according to Byock, is most likely to occur in hospice. "In nonhospice care, doctors and nurses tend to see dying patients as a bother—and therefore ignore them. But in hospice the focus is on the patient. There, once a certain comfort level has been achieved, the patient has an opportunity to take stock of his or her life, seek forgiveness and bestow it, and say goodbye to friends and family. One thing we're trying to do in Missoula is persuade people that the last part of their lives has value."

But this cannot occur until the "classic symptoms" of the dying process—shortness of breath, nausea, anxiety, delirium, and especially pain—have been brought under control, said Byock. "In many hospitals, physicians and nurses get busy and fail to note—let alone treat—these symptoms," he said. "We really need to change medical culture by teaching clinicians how important it is to respond rapidly to such crises. If we could shorten crises by even an hour, we would be saving dying people a lot of distress."

In Montana, responding to these crises used to be a complicated process that involved at least several people (nurse, physician, pharmacist), Byock noted. Today, however, registered nurses who provide palliative care are equipped with "crisis packs" of various medications and a standing physician's order enabling the nurse to administer them to patients. Emergency medical service personnel are also taught how to respond



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to crises. As a result, home care hospice patients now require fewer ambulance rides to the hospital, he said.

## SPIRITUALITY IN END-OF-LIFE CARE

Christina M. Puchalski, MD, an associate at the Center to Improve Care of the Dying, noted a new interest in the spiritual aspects of palliative care. "In 1992 I designed a course in spirituality in end-of-life care at the George Washington University Medical Center," she said. "My bosses predicted it would flop, but it was a big success. Today there are 40 such courses in U.S. medical schools, and the number is expanding fast."

Puchalski said dying patients often suffer from "a lack of meaning," along with their physical illnesses. "They ask: Why is this happening? Can God forgive me? What occurs after life ends? Although physicians cannot answer such questions, they should be equipped to help patients search for their own answers." But polls show that although a large majority of Americans believe faith can aid recovery, few physicians feel comfortable discussing spirituality questions, she said.

Puchalski said she routinely teaches her medical students to take from patients "spiritual histories" along with the usual medical histories. "A spiritual history is nothing more than talking to your patient about what gives life meaning," she said. To help students remember spiritual history questions, she has arranged them in an acronym, FICA:

*F* What is your *faith* or set of personal beliefs?

*I* Is your faith *important* to you? Does it affect how you take care of yourself?

*C* Are you part of a spiritual or religious *community*?

*A* How would you like me, your doctor, to *address* spiritual issues in your healthcare?

"I'm not inventing anything new here," Puchalski said. "Thirty or 40 years ago, all physicians knew that dealing with spirituality was an important part of medicine. It's interesting that we have to come up with acronyms to help doctors remember this basic stuff."

After taking a spiritual history, and if the patient agrees, Puchalski often refers him or her to a pastoral care professional, she said. "But I continue to address spirituality at each complete

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## ANALYSIS

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# MediCaring would extend the current Medicare hospice benefit to many more people.

physical exam. In my opinion, spirituality in patient care is an ongoing issue."

That is especially true of end-of-life care, Puchalski said. "Dying people don't brush these questions off. They are usually very ready to discuss them."

### THE MEDI-CARING DEMONSTRATION PROJECT

Although hospice provides the best end-of-life care, hospice is available to only a small percentage of dying people and for only a relatively brief period of time. This is so because few private insurance plans include hospice care, said Anne M. Wilkinson, PhD, an associate professor at the Center to Improve Care of the Dying. Medicare does offer a hospice benefit but limits it to patients with a life expectancy of six months or less. Unfortunately, Wilkinson said, the SUPPORT study showed that the lengths of "terminal" illnesses are difficult to predict and frequently exceed six months. Patients with cancer or AIDS tend to be the ones eligible for the Medicare hospice benefit. Patients with other severe, eventually fatal illnesses (for example, stroke, dementia, chronic lung or heart disease) are frequently not eligible.

Wilkinson, Lynn, and their George Washington University colleagues have proposed an "improved model of care for seriously ill people at the end of life." They call this new approach MediCaring.

MediCaring, Wilkinson said, would essentially extend the current Medicare hospice benefit to many more people. Under it, seriously ill patients would choose whether they spent their remaining days in acute care—possibly receiving "heroic" measures aimed at their cure or recovery—or in hospice care, where no such efforts would be made. MediCaring would be funded by capitated payments to multidisciplinary provider teams. Because it would reduce acute care interventions, MediCaring would not increase average medical costs, Wilkinson said. "Effectively, MediCaring would make it easy to get supportive care, which is now hard to get, and would make it harder to get ventilators and/or surgery, which are now easy."<sup>5</sup>

The proposal's supporters are currently seeking 10 to 12 sites for a nationwide MediCaring demonstration project. Funding from the Health Care Financing Administration for the project is also being sought, Wilkinson said.

—Gordon Burnside

☎ For more information, contact the Center to Improve Care of the Dying, 202-467-2233; e-mail: [www.abcd-caring.com](http://www.abcd-caring.com).

### NOTES

1. Efforts to improve end-of-life care by affiliates of three SCD:CCC members were cited in the conference papers. The organizations are St. Joseph Medical Center, Tacoma, WA (Catholic Health Initiatives); St. Mary's Health Center, St. Louis (SSM Health Care System); and St. Thomas Hospital, Nashville, TN (Daughters of Charity National Health System—East Central Region).
2. For recent coalition projects, see "Group Calls for Revolution in Care of the Dying," *Health Progress*, July-August 1997, p. 19; Gordon Burnside, "Mentoring Physicians," *Health Progress*, January-February 1998, pp. 32-38.
3. A study conducted by SCD:CCC in 1996 produced similar results. See *Living and Healing During Life-Threatening Illness, Supportive Care of the Dying: A Coalition for Compassionate Care*, Portland, OR, 1997.
4. Joanne Lynn and Anne M. Wilkinson, "Quality End-of-Life Care: The Case for a MediCaring Demonstration," Center to Improve Care of the Dying, Washington, DC, p. 4, photocopy, n.d.
5. Lynn and Wilkinson, p. 5.

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