



Symposium considers the art of medicine at the end of life

by Stephen J. Regnier, Editor

A one-day symposium—The Art of Medicine at the End of Life—convened in November 2007 at the University Club in New York, NY, and was attended by 100 registrants from 14 states (including 78 physicians representing 16 specialties) who treat and care for patients at the end of life. This symposium was jointly sponsored by the Cunniff-Dixon Foundation (see sidebar, page 15), the University of South Florida Health, and the H. Lee Moffitt Cancer Center and Research Institute in Tampa, FL.

Human psyche and mortality

The symposium's first speaker, Susan Block, MD, chief of psychosocial oncology and palliative care at the Dana-Farber Cancer Institute and Brigham and Women's Hospital, and co-director of Harvard Medical School Center for Palliative Care, Boston, MA, discussed the human psyche as it confronts mortality and engenders peace at the end of life.

Dr. Block discussed the very real “disconnection” with physicians that patients encounter at the end of their life, citing studies that indicate there is dissatisfaction with symptom management, physician communication, emotional support, and respectful care among family members of patients who died in the hospital; that fewer than half of physicians know whether patients

prefer to avoid cardiopulmonary resuscitation (CPR); and that 70 percent of patients in the last six months of life report there has been *no* discussion with their physicians about what to expect at the end of life.

Dr. Block stated that physicians on the whole tend to be overly optimistic when they communicate with patients, thus depriving them of an opportunity to prepare for the final days of their life.

Dr. Block explored with the audience members how they would define “peace” at the end of life. Among the components of peace discussed were the following:

- Acceptance of diagnosis
- Feeling well loved
- A sense of inner calm, harmony, and tranquility
- Tolerance of changes in physical appearance
 - Ability to enjoy life despite worries about illness
 - A sense that life is not yet over
 - A lack of anger about or a feeling of not feeling beaten by the illness
 - Lack of shame/embarrassment about illness

Dr. Block noted factors influencing peace and acceptance, including a therapeutic alliance with one's physician, encompassing feelings of connectedness and trust, discussions of the

prognosis with physicians, relationships with dependent children, religion and spirituality, and race and ethnicity. As to why peace matters with end-of-life issues, Dr. Block stated that peace is associated with reduced emotional and physical distress and suffering for the patient and the family; enhanced preparation for death and engagement with end-of-life decision making; less use of aggressive, nonbeneficial treatment at end of life; and more use of hospice/palliative care services.

Role of the hospital

The next speaker, Sharon R. Kaufman, PhD, professor of medical anthropology, department of anthropology, history, and social medicine at the Institute for Health and Aging, University of California, San Francisco, spoke on how the hospital as an institution shapes our dying. She noted that of all the players in the hospital, patients and families know the least about the way the hospital works and the limits of therapy. Many, perhaps most, people do not know what life support entails operationally and do not understand the limits of CPR or mechanical ventilation, according to Dr. Kaufman. “Most individuals do not understand the institutional rules to begin artificial ventilation with a breathing machine that drive much of medical practice in hospitals. [These individuals] are not prepared for the emotional turmoil and guilt that arise when they are confronted with complex, end-of-life options—such as whether to stop or start life-sustaining drugs—or [when they find themselves] in an emergency with no time to reflect,” she said.

Dr. Kaufman stated that hospitals are the root of public angst regarding dying—they are perceived as institutions that have too much technology and not enough compassionate care. “In the gray areas between life and death and end-of-life issues, the hospitals’ use of technology provides more questions than answers,” she said.

There are different pathways within a hospital—one of heroic intervention and one of a “revolving door” syndrome—that affect how patients are managed and how families are addressed during treatment. Hospice and palliative care

is an alternative pathway to medical care at the end of life, according to Dr. Kaufman, and is perhaps best suited to address at what stage of terminal illness one halts care and prepares for death.

Religious traditions

Abdulaziz A. Sachedina, PhD, Frances Myers Ball Professor of Religious Studies at the University of Virginia, Charlottesville, spoke about religious traditions at the end of life, noting that biomedical ethics at this time remain very secular. He said he believes the time has come to introduce religion as a partner to end-of-life medicine.

Dr. Sachedina said that there is a very human need to connect with one another during suffering and illness, and that religious and cultural beliefs can play a crucial role in preparing a patient to complete the whole life experience. This fact, he believes, is often lost to organized medicine. Human relationships are at the heart of religion in different cultures, and the need to be connected to other human beings and the value of human contact should not be discounted in end-of-life treatment regimens, Dr. Sachedina said.

Hospitals become too insensitive to the human needs of their patients, Dr. Sachedina said, adding that a person’s religious traditions can begin to ameliorate real and imagined insensitivities during illness and can facilitate a human connection between patient and family in the last days of life.

Legal/medical issues

Winthrop Rutherford, Jr., LLB, a partner with White and Case LLP in New York, NY, presented an overview of legal, liability, and medical issues at the end of life. He urged greater cooperation among physicians and lawyers in helping patients with end-of-life issues. “At present, there is little or no confluence between the two most important advisors that patients have at the end of their life,” he said.

Mr. Rutherford offered a short history of informed consent law in the U.S., along with a discussion regarding the development of current

guidelines governing health care proxies. Health care proxies need not be family members, and they can play a vitally important role in advising patients and families regarding end-of-life issues and ensuring that state legal statutes are known and followed, he said.

Ethics

Arthur Caplan, PhD, the Emmanuel and Robert Hart Professor of Bioethics, Center for Bioethics, University of Pennsylvania, Philadelphia, addressed the ethics of the transition to the end of life.

Dr. Caplan presented many questions for consideration. Should patients be able to hasten their own death by refusing a respirator, feeding tube, or other life support? If patients are unable to communicate their wishes, should others be able to decide for them? If so, who should make the decision—family members, medical professionals, or both? Does it matter if the patient is young or old? What if the individual is not terminally ill but severely and chronically ill? Is there a difference between refusing life supports and asking for medical intervention that would hasten death?

These and other questions have spawned a national dialogue on the quality of death and the rights of dying patients. Dr. Caplan reviewed as examples the cases of Karen Ann Quinlan and Terri Schiavo and the legal implications for palliative care.

Dr. Caplan posited that, regarding end-of-life ethical issues, the following needs to be done:

- Patients must reaffirm their right to monitor/control all medical care at the final stages of life
- Living wills alone are insufficient—patients need to add durable power of attorney to their legal documentation
- Organized medicine should establish the management of end-of-life treatment as a routine part of comprehensive medical care
- Hospice and palliative care should be reimbursable expenses
- End-of-life treatment should never be started without discussion as to when to stop such treatment
- Physicians should always offer their opin-

Cunniff-Dixon Foundation

The Cunniff-Dixon Foundation was created in 2005 in memory of Carley Cunniff and in recognition of Peter S. Dixon, MD. Ms. Cunniff died in January 2005 after a three-and-a-half-year battle with breast cancer. Dr. Dixon was her attending physician during her last year of life. “He was the guiding light who enabled Carley to die a peaceful death at home, with her family and loved ones,” said Andy Baxter, her husband and a founding member of the Cunniff-Dixon Foundation.

The mission of the foundation is to enrich the physician-patient relationship at the end of life. “Our goal is to educate individual physicians and inspire them to provide the kind of care at the end of life that we all wish for ourselves and our loved ones,” Mr. Baxter said. The foundation will present a series of continuing medical education conferences designed to educate physicians about end-of-life issues. Three such conferences in various locations are planned for this year.

In addition, the foundation is developing a Web site meant to be a leading source of information and interaction on palliative care. Initially, the Web site will target the medical community, with the hope of expanding it for the benefit of patients and their families. The Web site will be available at www.cunniffdixon.org and is expected to launch in the near future.

In the fall of this year, the foundation will award the first annual Cunniff-Dixon Prizes in recognition of clinical contributions and commitment to the practice of end-of-life medical care. Current plans are to award four prizes totaling \$95,000. Three of the awards will be in the amount of \$15,000 and will go to residents and/or fellows who have demonstrated a serious commitment to the field of palliative medicine and have already made a contribution, through practical research or clinical work. The fourth award—in the amount of \$50,000—will go to a physician who has demonstrated, through leadership and practice, a major, valuable commitment to end-of-life care.

Additional information regarding the foundation and the prizes may be obtained by contacting the Cunniff-Dixon Foundation, P.O. Box 800, Essex, CT 06426; tel. 860/434-6476; fax 860/434-8815.

ion regarding informed consent—their views need to be heard and considered

- All members of a medical/palliative care team should be on board regarding a course of treatment for terminally ill patients

Keynote address

Pauline W. Chen, MD, FACS—a general surgeon and writer from Boston, MA, who authored *Final Exam: A Surgeon's Reflections on Mortality* (New York: Vintage; 2008. ISBN 978-0307263537)—provided the keynote address during the symposium's lunch. She offered a poignant, introspective look at the care of several terminally ill patients she has encountered. She spoke of what drew her to the field of palliative care, the challenges it now faces, and to where she believes this field of medicine is progressing. (See Dr. Chen's related remarks on page 19).

Hospice/palliative care: When and how

Dr. Block and Peter S. Dixon, MD, led an interactive session with audience members regarding the current challenges faced in implementing palliative care. Among the insights provided during this session were the following:

- Patients often view hospice as abandonment by physicians or health care providers
- Physicians in the palliative care field often believe they are fighting the medical industry complex
- There are palpable respect issues associated with this field of medicine, as many physicians, nurses, and health care workers do not appreciate or respect palliative care professionals; there is a critical need for better public relations
- Many physicians (notably oncologists) equate palliative care with “symbolic” care

Physician-patient relationship

Edward M. Copeland III, MD, FACS—the Edward R. Woodward Distinguished Professor in the department of surgery at University of Florida College of Medicine, Gainesville, and the Immediate Past-President of the American College of Surgeons—spoke on the evolution of the physician-patient relationship.

Dr. Copeland offered his personal insights as to how a surgeon may create and foster a trusting relationship with the patient and family and how a surgeon should never underestimate the power of the “personal touch.” (An adaptation of Dr. Copeland's presentation appears on the next page.)

Q & A session

A question and answer session with a panel of faculty/presenters ended the symposium. Andy Baxter (see sidebar, page 15) offered closing remarks and acknowledged the efforts of course directors Dr. Dixon and Thomas S. Herman, MD, FACS, of Tampa, FL. □