THE CULTURAL BASIS OF INADEQUATE CARE

*To Provide Supportive Care of the Dying,
Our Society Must Learn to Live with Our Mortality*

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BY ANN NEALE, PhD

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Care of the dying in this nation is inadequate for a number of reasons, which are rooted in our culture as much as they are assignable to deficiencies in either the training and behavior of healthcare professionals or the practices of healthcare organizations.

Alicia Super and Lawrence Plutko's article in the March-April *Health Progress* ("Danger Signs," pp. 50-54) cites many of the factors contributing to inadequate care of the dying: lack of holistic medical training; a curative, aggressive medical culture; poor communication between physicians, patients, and families; a litigious climate; inadequate pain management; and problems with the healthcare system's structure and financial incentives. This article further explores several of these "difficult realities," underscoring the cultural foundation for inadequate care.

MEDICAL EDUCATION

The medical curriculum is woefully inadequate when it comes to courses about and experience with dying patients.[1] In 1993 and 1994 less than 4 percent of medical schools even required a separate course in care of the dying. Less than 20 percent of medical schools used hospice rotations, and most of these were probably optional. Even when medical students did have lessons in care of the dying, the lecture method predominated, allowing little personal contact with dying patients.

Given these shortcomings, especially in the nonmedical aspects of care of the dying, it is understandable that physicians report being more comfortable treating organic symptoms such as bedsores, nausea, vomiting, and constipation than treating emotional and subjective symptoms such as breathlessness, depression, pain, and anxiety.

AGGRESSIVE TREATMENT

Ethicist Daniel Callahan speaks of the way our treatment of persons at the end of life deforms their experience of dying. "Technological brinksmanship" (the pursuit of aggressive treatment as far as it can go with the intention of pulling back at just that point where care becomes futile) makes appropriate, compassionate care of the dying very difficult.[2] Callahan cites the irony in this situation—that death is not better managed in this era of greater biological knowledge, more powerful analgesics, and other sophisticated tools in our medical armamentarium. Indeed, he notes that this technology fuels an attitude that denies mortality. It creates a medical arrogance based on a belief that death can be overcome.

PAIN MANAGEMENT

Physicians themselves report that they are more concerned about overtreatment of dying persons than undertreatment. The exception is pain management. As T. Patrick Hill writes, "Eighty-five percent of medical attending physicians, 83 percent of surgical attending physicians, and 84 percent of house officers indicated that the most common form of narcotic abuse in the care of the dying is undertreatment of their pain."[3] Callahan corroborates this phenomenon by noting that the medical classic, *Cecil Textbook of Medicine*, devotes only 5 of its 2,300 pages to pain, and only 3 pages to treatment for those who are dying.[4]

In addition to physical pain, persons who are dying also experience psychological distress and other kinds of spiritual and existential suffering that care givers frequently fail to address. Despite growing recognition that dying persons need emotional and spiritual as well as physical attention, multidisciplinary care of the dying has not found sufficiently wide acceptance. Because medicine's traditional independence and dominance do not lend them-

selves to a collegial approach, medical care often does not well serve the comprehensive needs of persons who are dying. Hierarchical patterns of care need to yield to multiprofessional teamwork for palliative care to assume its rightful place in the care spectrum. Concomitant changes in reimbursement and financial incentives are also required.

HOSPICE

The growth of hospice programs demonstrates an increasing public awareness of a different, more comprehensive philosophy of care for the dying. Indications are, however, that the public's awareness is increasing more rapidly than that of the medical community.

In 1983 Congress enacted the Medicare Hospice Benefit Act, spurring acceptance of and participation in hospice, although hospice still has not secured a place in mainstream healthcare. In 1994, 340,000 persons died in hospice programs, representing only 10 percent of deaths that year.[5] No doubt it would have been more appropriate for many of those who died in hospitals to have died at home or in a nursing facility. An encouraging sign is that the Health Care Financing Administration is exploring the possibility of establishing a diagnosis-related group for palliative care.[6] Presumably that policy change would moderate some technological brinksmanship, improving the hospital death experience.

COMMUNICATION

Effective physician-patient communication is recognized as key to efficacious care, especially for patient comfort. It seems obvious that improving such communication should improve care at the end of life. Yet a recently concluded study—designed, in part, to enhance the effectiveness of physician-patient communication about end-of-life treatment decisions—found that attempts at better communication failed to improve care of the hospitalized dying.[7] In fact, in a society that does not deal well with death, it is probably unrealistic to expect the medical establishment to do so. Nevertheless, it is disturbing that physicians often do not know or do not heed individuals' wishes about their end-of-life care. In American society, fixed as it is on autonomy and self-determination, this failure gives rise to clinical, legal, and moral battles.

DEATH-AVERSE CULTURE

Most likely, as Callahan claims, the fundamental reality underlying our inadequate care of persons with life-threatening illnesses is our death-averse culture. As recently as the beginning of this century, nearly everyone had had a personal experience of death. In 1900 the rate of infant mortality was 16

times today's rate. The overall death rate since the turn of the century has declined by 50 percent. Communicable diseases have been all but eliminated as a cause of death. Now our experience of death is more likely to be the lengthy, debilitating decline of degenerative diseases. Death has moved from a public, community event in the home, to the hospital—a less accessible, private, individual sphere, the domain of medical specialists. Callahan describes the phenomenon as the "secularization of death," replacing a religious with a medical response.[8]

From a familiar, if sad, occurrence that touched almost every household, death has become a stranger. Indeed, it has become an enemy—unmentionable not only by ordinary people but also by healthcare professionals, who virtually always regard death as a negative patient outcome. Our culture seems far more inclined to deploy awesome medical technology to delay death than to reflect on the profound issues posed by our mortality.

A CHALLENGE TO THE PREVALENT CULTURE

The collaborators in Supportive Care of the Dying: A Coalition for Compassionate Care, the Catholic multisystem project to change how we care for the dying, recognize the significance of these cultural challenges (see **Box**). Our comprehensive supportive care model involves early intervention directed to identified needs of both persons with life-threatening illness and their families. It is based on values

SUPPORTIVE CARE OF THE DYING: A COALITION FOR COMPASSIONATE CARE

The Supportive Care of the Dying coalition was founded in 1995 by the Catholic Health Association and five Catholic healthcare systems: Carondelet Health System, St. Louis; Daughters of Charity National Health System, St. Louis; Franciscan Health System, Aston, PA; PeaceHealth, Bellevue, WA; and Providence Health System, Seattle. The coalition's goals are to:

• Assess the current level of care to identify, develop, and share delivery models pertaining to all dimensions of care for the suffering and dying

• Develop and implement a paradigm of compassionate care that integrates ethical, clinical, and spiritual dimensions

• Develop educational programs for professional care givers, families, and the broader community

• Establish criteria and measurement guidelines to assess processes, outcomes of education, compassionate care services, and methods of assigning accountability for these guidelines and processes

• Foster networking among care givers and identify resources within the broader community that support compassionate care of persons with life-threatening illness

INADEQUATE CARE

that honor life, respect human dignity, and cherish and support the most vulnerable among us. Although these values are embraced by many in our pluralistic world, countervailing forces in society at large, and medicine in particular, often obscure their realization when it comes to care for the dying.

We plan—through solid research, collaboration with our communities and other care givers, and perseverance—to develop a model for end-of-life care that will, if only gradually, transform the current fearsome experience of death. We intend to help care givers and society better acknowledge, comfort, and support one another in the face of this inevitable human event.

To the extent that our model is successful, we as a society may learn to live with our mortality, and we as care givers may begin to create a community of care and support for those who are dying. Perhaps we can *begin* to build in our communities what Callahan suggests is lacking in this country—a "sustaining or supportive general culture for grappling with the human reality and importance of death."[9] □

☎ *For more information on the coalition, contact Project Coordinator Alicia Super, Providence Health System, 4805 NE Glisan St., 2E09, Portland, OR 97213-2967; 503-215-5053.*

NOTES

1. T. Patrick Hill, "Treating the Dying Patient: The Challenge for Medical Education," *Archives of Internal Medicine*, June 26, 1995, pp. 1,265-1,269.
2. Daniel Callahan, "Pursuing a Peaceful Death," *Hastings Center Report*, July-August 1993, pp. 33-38.
3. Hill, p. 1,269.
4. Callahan, "Pursuing a Peaceful Death."
5. BNA Health Care Policy Report, May 8, 1995.
6. Bruce C. Vladeck, "End-of-Life Care," *JAMA*, August 9, 1995, p. 449.
7. Alfred F. Connors, et al., "A Controlled Trial to Improve Care for Seriously III Hospitalized Patients," *JAMA*, November 22-29, 1995, pp. 1,591-1,598.
8. Daniel Callahan, "Frustrated Mastery: The Culture of Death in America," *Western Journal of Medicine*, September 1995, pp. 226-230.
9. Callahan, "Frustrated Mastery," p. 229.