REFLECTIONS ON DEATH IN AMERICA

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"First and foremost, doctors, nurses, and other health professionals need better training in the care of the dying, especially in the relief of pain. Physical pain is what people fear most about dying. A dying person in pain cannot think about anything else, leaving no room for coming to terms with death, for reviewing one's life, putting one's affairs in order, for saying good-bye."

MY FATHER DIED at home in 1963. He was terminally ill. Although he agreed to an operation, he didn't particularly want to survive it because he was afraid that the combination of the illness and the operation would invade and destroy his autonomy as a human being. Unfortunately, that in fact is what happened. After the operation he had very little time left. I'm afraid I wrote him off at that point. I was there when he died, yet I let him die alone. I could see him, but I wasn't at his bedside. The day after he died I went into the office. I didn't talk about my father's death. So I kind of denied his dying, I certainly didn't participate in it.

My mother's death was more recent. She had joined the Hemlock Society and had at hand the means of doing away with herself. I asked her if she needed my help; I offered it, although I wasn't particularly keen to do it. But I would have helped her because I felt that I owed it to her. At the point of decision, however, she did not want to take her

own life, and I'm glad she didn't. Her decision gave the family a chance to rally around and be there as she prepared to die. And this time we did maintain good contact right to the end.

She had this experience, which is described in Kubler-Ross, of walking up to the gates of heaven, and I was accompanying her. She told me she was worried that she might drag me with her. So I reassured her that I was firmly ensconced on this earth and she should not worry. Her dying was really a very positive experience for all of us because of the way she handled herself and the way the family, not just me but particularly my children, could participate in it.

These personal experiences with the deaths of my parents are some of the reasons I established the Project on Death in America to promote a better understanding of the experiences of dying and bereavement and by doing so help transform the culture surrounding death.

Through its Faculty Scholars Program and Grants Program, the project supports initiatives in research, scholarship, the humanities, and the arts, as well as innovations in the provision of care, public education, professional education, and public policy.

What do we want to transform and why? An explanation begins with a small matter, the name of our project. It took a considerable amount of discussion to rid ourselves of clever euphemisms and settle on a name that states our purpose directly, even starkly: the Project on Death in America.

In America, the land of the perpetually young, growing older is an embarrassment, and dying is a failure. Death has replaced sex as the taboo subject of our times. Only our preoccupation with violence breaks through this shroud of silence.

Even doctors, especially doctors, don't like to think about death. A federal pamphlet for physicians on HIV infection recommends making arrangements for the care of the children when the patient becomes sick, but says nothing about the need for long-term plans for when the patient dies. It is easier to find descriptions of the way people die and what can be done to ease their death in the medical textbooks of the turn-of-the-century than in today's voluminous literature on the treatment and cure of diseases.

This emphasis on treating disease, instead of providing care, has altered the practice of medicine. People live longer, surviving four or five illnesses before dying. But the healthcare bill grows with every illness. Our success has also brought other unintended consequences. We have created a medical culture that is so intent on curing disease and prolonging life that it fails to provide support during one of life's most emphatic phases—death. Advances in high-technology interventions have contributed to this weakness in our medical system, deluding doctors and patients alike into believing that the inevitable can be delayed almost indefinitely.

The reality of death and the perceptions of the participants—the dying person, the doctor, the family members—are separated by a wide gap. We need to bring the two into closer alignment. Doctors who are on a first-name basis with disease must reacquaint themselves with the patient. They must recognize that, by focusing exclusively on conquering disease and prolonging life, they abandon the dying when, in their own words, there is nothing more to be done.

Up to 80 percent of people die in hospitals, yet, for most people, hospitals are not a good place to die. Hospitals are set up to take care of acute illnesses, and dying is not an illness. It doesn't belong to an official medical category, it has no billing code that would permit reimbursement for the hospital and the physician. If you go to a hospital to die, the doctors have to find something wrong with you, something to treat, like pneumonia or dehydration, or they cannot admit you. They hook you up to tubes and machines and try to fix a condition that isn't fixable. The need to arrive at a reimbursable diagnosis changes the reality. The doctors and nurses are working to prolong life, instead of preparing a patient for death. The ideal of a peaceful death is impossible in such an alien setting, under such extreme conditions.

A peaceful death is more likely to be achieved at home in familiar surroundings that are more conducive to the comfort and ritual of leave taking from family and friends. Only 20 percent of people die in their own home, in a nursing home, or in a hospice. Hospices offer the kind of palliative care that should be routine procedure in every institution that cares for the dying. Proper care

includes the control of pain and other symptoms as well as attention to the psychological and spiritual needs of the patient. To provide this care, hospices employ teams of doctors, nurses, social workers, and bereavement counselors.

The recommendations that follow from these observations are obvious. First and foremost, doctors, nurses, and other health professionals need better training in the care of the dying, especially in the relief of pain. Physical pain is what people fear most about dying. A dying person in pain cannot think about anything else, leaving no room for coming to terms with death, for reviewing one's life, putting one's affairs in order, for saying goodbye. Therefore, pain relief must come first.

Second, hospitals must be required to develop and adopt a comprehensive billing code for terminal care. This single change would go a long way towards removing the hypocrisy that now surrounds a hospital's treatment of the dying and freeing doctors and nurses to provide the kind of care that doesn't rely on technology—such as the simple act of paying attention to a dying person, holding their hand, listening, and comforting them.

Third, we must increase the availability of hospice services for terminally ill patients, removing restrictions on admittance and enhancing reimbursement regulations. We should consider laws that permit next of kin to decide to forgo life-sustaining medical interventions even when a patient's wishes are not known. The government may have to help family members financially so that they can take care of the dying at home by the least expensive means. These are only a few of the approaches to transforming the culture of dying that our project is exploring.

How much will all this cost? Can we afford to care for the dying properly? The number of people dying in the United States currently stands at 2.2 million annually. Increases in cancer and AIDS deaths and the aging of the baby boomers will cause this figure to climb faster than the population. Today 1 in 8 Americans is 65 years or older. In 30 to 40 years, 1 in 5 will be in that age group. The average life expectancy for those reaching age 65 is already 81 for men and 85 for women. The fear is that the costs of care for the elderly will drain the national treasury. Like most fears, this one is based on a myth, the popular perception that elderly, terminally ill patients consume enormous amounts of resources shortly before they die.

It is true that nearly half of all medical expenses are incurred in the last six months of people's lives. But it is also true that medical expenditures in the last year of life are lower for people 80 years and older than for those in younger age groups. Aggressive, life-prolonging interventions, which may at times go against the patient's wishes, are much more expensive than proper care for the dying.

This brings me to that hotly debated subject, physician-assisted suicide. This is the one aspect of dying that is talked about everywhere—on television, in public forums, in newspaper headlines and serious journal articles, and in the courts. I believe in personal autonomy; I believe people should be allowed to determine their own end. But I also recognize that legalizing physician-assisted suicide could have unintended consequences, leading to all kinds of abuses. The issues need to be carefully weighed. Very few terminally ill patients would avail themselves of the opportunity even if physician-assisted suicide were legalized. After all, my mother refused my help and I am glad she did. The Project on Death in America concerns itself with the vast majority of people who are not looking for physician-assisted suicide, and there is much work to be done.

As people come to terms with death, recognizing it as a fact of life, then the demand for physician-assisted suicide, as well as for unnecessary medical interventions, will drop. That is one way I hope our efforts will influence the culture of dying.

This essay was adapted from a speech given at the College of Physicians and Surgeons of Columbia University in November 1994 soon after the establishment of the Project on Death in America.

Eugene Richards' film, *but, the day came* documents the journey of an independent 92-year-old Nebraska farmer to a nursing home.