

Death and Dying - Medicalization Of Dying

In 1900 most Americans died at home, often surrounded by multiple generations of family members. By 1950 approximately half of all deaths occurred in hospitals, nursing homes, or other institutions. By the mid-1990s, 80 percent of Americans died in medical institutions, attended by paid staff. Persons over age sixty-five comprised less than 13 percent of the population, yet they represented 73 percent of all deaths in the United States in the mid-1990s. At the beginning of the twenty-first century, 55 to 60 percent of persons over the age of sixty-five die in the acute-care hospital, though patterns vary considerably across the nation (Institute of Medicine). Those persons fall into two distinct groups. The first includes elderly who were functioning independently until they were struck by a serious illness such as heart attack, stroke, or fractured hip. Most of those patients receive relatively intensive care. The second group includes people who are older, frail and debilitated, have multiple degenerative and chronic conditions, but are not clearly dying. The second group is larger, comprising 70 percent to 80 percent of elderly patients in the hospital. Individuals in that group may require repeated hospitalizations for supportive or intensive care, to stabilize conditions and treat acute problems (Scitovsky and Capron).

As the place of death has shifted from the home to the hospital, medicine, as a system of knowledge, has become the dominant cultural framework for understanding death, the process of dying, and how to act when death approaches. Health professionals have the assumed responsibility, once held by family and community, for the care of persons at the end of life, and they now widely influence how that care is understood and delivered. Physicians have become the gatekeepers of the dying transition in the United States. They, rather than the dying person or family, define when the dying process has begun. This is most obvious in the hospital intensive care unit (ICU), where the inevitability of death frequently is not acknowledged until the end is very near, and the discontinuation of life-sustaining treatments often signifies the beginning of the dying process. Moreover, in the ICU, medical staff members are able to orchestrate and control the timing of death (Slomka).

A growing elderly population, cultural ambivalence about the social worth of the frail and very old, medical uncertainty about whether or not to prolong frail lives, and rising health care costs contribute to

controversy both among health professionals and the wider public about decision-making and responsibility at the end of life. The costs of medical care, and especially the costs of intensive care, are high in the last months of life. Those rising costs have been the source of debates about rationing health care to elderly persons in order to reduce health care costs. For many people both within and outside of medicine, the value of prolonging life by technological means competes with the value of allowing death to occur without medical intervention. That cultural tension has given rise to a vast array of seemingly insoluble dilemmas about the management of dying. A vast literature in bioethics illustrates dilemmas in treatment and care for the dying elderly for which there are competing claims and no distinct solutions. Common dilemmas about technologically prolonging life include the following: whether or not to artificially feed (through a feeding tube) a person who can no longer feed him or herself; whether or not to place a person who has difficulty breathing on a mechanical ventilator; and whether or not to admit a dying person to an intensive care unit.

As more technological and clinical innovations become available, there is more that can be done to postpone death. The technological imperative in medicine — to order ever more diagnostic tests, to perform procedures, to intervene with ventilators, medications, and surgery in order to prolong life or stave off death whenever there is an opportunity to do so — is the most important variable in contemporary medical practice, influencing much decision-making at the end of life. There are no formulas that health professionals, patients, or families can use to decide between life-extending treatments and care that is not aimed at prolonging life. It is very common for patients, family members, and health professionals to feel obligated to continue aggressive medical treatment even though they do not wish to prolong the dying process.

The largest study ever conducted on the process of dying in the hospital was carried out in five university hospitals across the United States over a four-year period beginning in 1989 (SUPPORT Principal Investigators). In the first two-year phase of the project, 4,300 patients with a median age of sixty-five who were diagnosed with life-threatening illnesses, were enrolled. The SUPPORT investigators concluded that the dying process in the hospital was not satisfactory. For example, only 47 percent of physicians knew when their patients wanted to avoid cardiopulmonary resuscitation (CPR); 38 percent of patients who died spent ten or more days in an ICU preceding death; 46 percent of *Do Not*

Resuscitate (DNR) orders were written within two days of death even though 79 percent of the patients had a DNR order; and for 50 percent of the conscious patients, families reported moderate to severe pain at least half the time in the three days preceding death. Even when a focused effort was made to reduce pain and to respect patient wishes regarding end-of-life care, no overall improvement in care or outcomes was made.

The technological imperative shapes activities and choices in the hospital even though death without high-technology intervention is valued by many in principle. One survey of nurses and physicians revealed that health professionals would not want aggressive life prolonging treatments for themselves, and many would decline aggressive care on the basis of age alone (Gillick, Hesse and Mazzapica). Approximately half of physicians and nurses interviewed in another study stated they had acted contrary to their own values by providing overly aggressive treatment (Solomon et al.).

Philosopher Daniel Callahan has noted that American society, including the institution of medicine, has lost a sense of the normal or natural life span, including the inevitability of decline and death. Callahan and other critics challenge the medical imperative of considering death as an option, one of several available to practitioners and consumers of health care (Callahan). Medicine pays little credence to the biological certainty of death; the tendency instead is to believe that dying results from disease or injury that may yield to advances in technology (McCue). Yet there is a lack of clarity about what constitutes normal aging and decline and what distinguishes them from disease.

Family members are sometimes confronted with the choice of prolonging the life of a person who they consider to have died already as the result of a stroke, a coma, or other serious condition that destroys or masks the personality of the individual. Such *social death*, when the person can no longer express the same identity as before the health crisis, occurs days, weeks, months, or years before *biological death*, when the physical organism dies. The discrepancy between social and biological death is one of the most difficult features of contemporary medical decision-making.

The use of hospice programs, in which clinical, social, and spiritual support are given to dying persons and their families without the intention of prolonging life, began in the United States in 1974. Hospice

embodies a philosophy, originating with Dr. Cicely Saunders in Great Britain, that pain control, dignity, and the reduction of spiritual and psychological suffering are the most important goals of patient care as death approaches. Hospice care, delivered both in the home and institutional setting, has been growing steadily since the 1980s. Yet in 1995 only about 17 percent of all deaths (all ages) took place in a hospice setting. The notion of *palliative care*, medical care that seeks to reduce and relieve symptoms of disease during the dying process without attempting to effect a cure or extend life, is gaining support and acceptance among health care practitioners and the public, but the desire to control and conquer end-stage disease still strongly influences most medical thought and action (Institute of Medicine 1997).

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