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Death, Dying, and Hospice Care

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The experience of death and dying has changed in the United States since the 19th century. Back then, most people died in their homes surrounded by family and friends. Rituals included adults as well as children, especially in keeping vigil as the dying person slowly drifted into death. Beginning in the 20th century, the rate of infant mortality dropped sharply. Life expectancy increased by approximately 30 years during the 20th century, and now a newborn is expected to live well into the seventh or eighth decade of life. The causes of death have also shifted from infectious diseases, such as diarrheal diseases, respiratory infections, and parasitic diseases (including typhoid fever, diphtheria, and tuberculosis) that preyed on the very young, to chronic diseases (including cancer, stroke, and cardiovascular diseases) that affect mostly the elderly. This epidemiological shift in the patterns of disease is attributed to better hygiene and housing, improved diet, safer roads and work conditions, safer transportation vehicles, and the unprecedented development of medical technology starting with the advent of antibiotics during the mid-20th century.

During the early 1900s, approximately 80% of deaths occurred at home; only 20% occurred in institutional settings (hospitals and nursing homes). By the early 21st century, this trend was reversed, and now nearly 80% of deaths occur in hospitals and nursing homes surrounded by advanced medical technology, including ventilators, dialysis machines, and artificial feeding tubes. The availability of technologically sophisticated medical interventions has resulted in the extension of life in debilitated conditions that prolong the natural process of dying, leading to the development of hospice care.

The hospice movement was born out of the philosophy that it is possible to maintain a high quality of life for as long as possible but to give priority to the*quality* of life rather than the*quantity* of life. This is achieved through surrounding the person experiencing a life-limiting illness with loved ones and through focusing on palliative and spiritual care rather than on medical interventions that prolong the dying process. Hospice is not necessarily a place; it is a program of medical, social, and spiritual services provided to the dying individual and his or her family. Hospice services can be provided in the person's home, a hospital, a nursing home, an assisted-living facility, or a free-standing hospice center. In the United States, anyone facing a life-limiting illness can qualify for hospice services regardless of age, sex, religion, race, or medical diagnosis and also regardless of ability to pay. Services are funded by all traditional medical funding sources such as Medicare, Medicaid, health maintenance organizations, private insurance companies, and private funding.

St. Christopher's Hospice, the first-ever hospice, was founded in 1967 in London by Dame Cicely Saunders. The concept of hospice care was later brought to the United States by Florence Wald, dean of the Yale School of Nursing, who invited Saunders to become a faculty member at Yale. The Connecticut Hospice, the first hospice in the United States, was then opened in 1974 in Branford, Connecticut. Hospice services have become increasingly accepted over the years, and in 2001 approximately 3,200 hospice programs provided care to 775,000 patients in the United States alone. One fourth of all those who died in 2001 did so while receiving hospice services. Hospice services are provided by a multidisciplinary team that includes physicians; nurses; home health aides; social workers; spiritual counselors; volunteers; and speech, physical, and occupational therapists.

During the 19th century, high infant mortality and the involvement of the extended family made death a familiar and accepted part of life. With the advent of antibiotics, vaccines, and other life extensions, people's attitude changed to one where death was treated as a taboo topic. Cultural attitudes about death have since progressed from death denying to death recognizing, thanks to the efforts of Elisabeth Kübler-Ross, the Swiss psychiatrist who published the landmark book*On Death and Dying* in 1969. This book of interviews with dying cancer patients identified the stages of grief that have become the gold standard: denial, anger, bargaining, depression, and (finally) acceptance. Critics later discounted Kübler-Ross's writings because of the implication that all humans react similarly and that emotions occur in a linear fashion, charges that Kübler-Ross denied. Some people clearly experience death in the way Kübler-Ross described, but others may skip one or more of the stages or may vacillate repeatedly between the stages. In spite of the controversial aspects of her writings, Kübler-Ross is indisputably credited with breaking down the barriers surrounding discussions of death and dying and spearheading many of the now familiar interdisciplinary interventions.

One of the most valued services provided by hospice programs is helping family members and other caregivers with their grief, mourning, and bereavement following the death of the hospice patient. Whereas bereavement refers to the specific death event and the feeling of deprivation of a valuable part of life, grieving over the loss of life, physical and social functions, and/or companionship may start at any time—even before death occurs. This is referred to as*anticipatory grief.* Grief can be triggered when social isolation becomes the norm after serious life-limiting illness develops. Frequently, caregivers are so involved in the care of the terminally ill person that social contacts diminish incrementally, resulting in devastating social isolation. Social isolation affects the terminally ill person as well as the caregivers, and social death, or the gradual withdrawal from all social contacts and responsibilities, becomes the norm. Anticipatory grief can affect all members of the terminally ill person's milieu, even when death does not actually occur (i.e., during a relapse or remission of the disease). The fact that death is yet to occur delays the normal processes of grief and presents a complicated course of coping with the loss. Grief is exhibited in physical, emotional, and behavioral reactions. Physical reactions consist of loss of sleep and/ or appetite and/or a heavy feeling on the chest. Emotional reactions of anxiety, sadness, anger, and depression are common. Behavioral reactions are expressed by hitting one's chest, crying, and/or even exhibiting extreme stoicism.

Eventually, healing starts through the process of mourning, a time that allows for integrating the loss in everyday activities. People exhibit to the world that they are in a period of mourning by wearing a black armband or clothing of certain colors (e.g., white in some Asian and north African countries, black in Europe and the United States), avoiding appearances of enjoyment (by withdrawing from activities such as going to the theater and even watching television or listening to the radio), or by not wearing makeup or cutting one's hair (common in some Native American tribes). Mourning rituals may be culture specific, but the experience of grieving the loss of a loved one is general and universal. Social norms dictate when the mourning period ends. When the mourning period is officially over, a return to normalcy and to routine life experiences, such as working and resuming social connections, is expected. An assessment may be needed to determine whether the bereaved is progressing effectively in the mourning process or whether the grief is complicated and unresolved. This condition can develop if the death of the loved one occurred unexpectedly (as in case of the death of a child), if there are unresolved conflicts between the deceased and the person experiencing the grief, or if the caregiver was immersed in caregiving duties and responsibilities immediately preceding the death.

Complicated and unresolved grief resulting from the loss of a loved one must be distinguished from major depression, which is a psychiatric diagnosis. Complicated grief is characterized by an inability to cope for more than 6 months after the occurrence of death. Feelings of disbelief, anger and bitterness, yearning and longing for the deceased person, and feeling preoccupied by the death are examples of this experience. Complicated grief can be diagnosed by administering assessment tools such as the Inventory of Complicated Grief. Hospice professionals are trained to recognize the variety of grief symptoms at very early stages and can either provide appropriate counseling themselves or make referrals to other specialists who routinely deal with grief counseling.

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See also

- Bereavement and Grief
- Palliative Care and the End of Life

Further Readings and References

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