

PALLIATIVE CARE AND HOSPICE

- I. Definition and Scope.
- II. The Development of Palliative Care.
- III. Ethical and Policy Issues in Palliative Care and Hospice.

Literature

Devine, Richard J. *Good Care, Painful Choices: Medical Ethics for Ordinary People*. Mahwah, NJ: Paulist Press, 2004.

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The terms palliative care and hospice are frequently used interchangeably to describe an approach to the care of individuals who are likely to die in the relatively near future from serious, incurable disease, for whom the principal focus of care is quality of life and support for the patient's family. The terms gained currency in the last third of the twentieth century as a result of significant changes in the leading causes of death in the developed countries of the industrialized world. In these countries prior to 1900, most people died relatively quickly, usually from acute, infectious diseases. They typically died at home, attended by family and friends. Because little in the way of medical technology was available to prevent or delay death, the costs of care were low, and the dying person and her

caregivers could emphasize the interpersonal and spiritual aspects of dying. By contrast, at the beginning of the twenty-first century most people in the developed world die from chronic, degenerative diseases such as cancer, cardiovascular disease, lung disease, and degenerative neurological disease. Death usually follows a prolonged period of progressive loss of function and numerous distressing symptoms, of which pain and shortness of breath are the most feared by patients, along with fear of the unknown. Because considerable medical technology now exists that can postpone death, costs are often high and most people die in hospitals or nursing homes, attended by strangers. For patients who die at home, the financial, physical, and emotional burdens of caregiving fall heavily on isolated nuclear families, and predominantly on women.

Hospital-based teams were created to provide care for patients in the hospital units where they were still receiving treatment intended to cure or slow the progress of their underlying disease. Things could also be improved when people were being cared for at home, where most wanted to remain as long as possible, though, contrary to what has always been said, not necessarily to die there. A range of services was developed to assist primary physicians caring for people at home, including home visits by nurses and other professionals and day-care units for patients who could be brought into a center for clinical assessment and creative occupational therapy.

Palliative care was no longer synonymous with «care of the dying». Yet, as the field has developed, it has struggled to define itself in a way that captures its broader scope reflecting its appropriateness for patients earlier in their disease process, who are not imminently dying—without resorting to euphemisms chosen to disguise the fact that the care is for people who, sooner rather than later, will die of their illness. The most commonly used definition is that devised by the World Health Organization. It emphasizes that the principles of palliation—the relief of physical, psychosocial, and spiritual distress, and respect for the needs of relatives—are appropriate from the time of diagnosis. In an attempt to produce a more succinct definition, called for when palliative medicine was recognized as a

medical specialty in the United Kingdom in 1987, palliative care was defined as the study and care of patients with active, progressive, far-advanced disease and a limited life expectancy, for whom the focus of care is the quality of life.

This definition does not limit palliative care to people with malignant disease, nor does it state a prognosis in terms of months or weeks. It is worded so as not to be confused with care of the elderly, care of the chronically ill, or care of the incurable (which would embrace many of the conditions seen daily by physicians). Unfortunately, it omits mention of relatives, or the fact that palliative care can be provided only by an interdisciplinary team. Its strength lies in its unequivocal focus on quality of life rather than on cure or prolongation of life, the declared objectives of much modern medical care.

J. Andrew Billings, who reviewed many of the competing definitions, concluded that the following definition achieves the best balance of completeness and concision:

Palliative care is comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a terminal illness and for their families. Key elements for helping the patient and family live as well as possible in the face of life-threatening illness include assuring physical comfort, psychosocial and spiritual support, and provision of coordinated services across various sites of care.

Two further statements, endorsed by the government of the United Kingdom, have been found challenging and helpful:

It is the right of every person who needs it to receive high quality palliative care, irrespective of his or her diagnosis.

It is the responsibility of every clinician to provide high quality palliative care.

In applying these principles in the complex, highly differentiated world of the health professions, it is helpful to note that palliative care can be provided at three levels: principles, techniques, and specialist care.

Palliative care principles are integral to all good clinical care, and they are applicable at every stage of a patient's care, whatever the nature of the illness. Every doctor and nurse should apply these principles, even when they are still defining the nature and cause of an illness or its symptoms.

From the handful in operation in 1967, there are now more than 6,200 palliative care programs in over 100 countries. In its birthplace, the United Kingdom, palliative care services are readily and freely accessible to all. The National Health Service runs one-fifth of these services, and 25 percent of the operating costs of the others are met by government, the balance being met from voluntary funding. A typical palliative care in patient unit in the United Kingdom, with 10 to 100 beds, admits annually twenty to twenty-five patients per bed, where each will stay for an average of eleven to fourteen days. The portion of patients able to return home varies between 40 and 60 per cent, higher if there is an effective community palliative care service and a day unit. Seldom do more than 15 per cent of patients who have conditions other than cancer receive palliative care in the United Kingdom, a considerably smaller percentage than in the United States.

Though palliative care services are being developed in many countries, most are modeled on those of the United Kingdom and the United States, rather than being designed to meet local needs and cultures. Palliative care is still not available to the 75 per cent of the world's population, for whom curative treatment of life-threatening disease is either unavailable or inaccessible.

Many of the ethical issues that arise in the care of the dying are similar to issues that arise in many other areas of healthcare, such as truthfulness and confidentiality, decision-making authority in the professional-patient relationship, the appropriate use and allocation of technology and other healthcare resources. Other issues are more commonly associated with the care of the terminally ill, though not absent from other arenas, such as decision making for patients who have lost the capacity to make or communicate their own decisions, withholding

or withdrawing life-sustaining treatment, and hastening death by assisting in suicide or through active euthanasia.

The latter issue tends to receive the greatest attention from bioethics scholars and policymakers. Moral distinctions between various actions or choices that can hasten the time of death can be exquisitely fine. Yet, for all the persistent and intense debate surrounding the issues of suicide and euthanasia, «terminal sedation» and the doctrine of double effect, or the differences, if any, between «allowing to die» and «causing to die», another set of issues are no less vexing and affect far more people. These are the Questions of access to and quality of palliative care services. It is true that dying at home is an imperfect marker for the adequacy of palliative care. In fact, in most developed countries, the better the palliative care provision in hospitals and the community, the fewer the number of people who die at home, with home deaths now approaching 20 per cent in most European countries. A more telling statistic is that of patients who received hospice care in 2000, one-third died within seven days of admission, despite the six months of benefits allowed under the Medicare hospice program. Although the reasons for these trends are still being investigated, the following are likely to be significant contributing factors: the difficulty of making precise estimates of life expectancy-as is required for Medicare hospice eligibility- especially for diseases other than cancer; patients' reluctance to accept the label «terminally ill»; the requirement that patients forgo Medicare reimbursement for treatments with curative intent; and many physicians identification of a hospice referral with «giving up».

Worldwide, the challenge of access to competent palliative care is no less daunting. Among the principal causes for alarm is the number of people living with HIV/AIDS- estimated by the United Nations at 40 million at the end of 2001-and the large projected increase in deaths from tobacco products, which the World Health Organization predicts could triple by 2020 from the 2000 level of 3.5 million. In both cases, almost all of the increase is expected to occur in the developing world. Global efforts to teach the principles of modern palliative care,

and to incorporate them in healthcare systems, are lagging far behind the manifest need, despite curative technologies and medications remaining unavailable or unaffordable for most of the world's poor.

Where palliative care is available, there is the challenge of providing care in ways that respect different cultural and religious views. Most professionals who enter the field do so because they want to help people to die well. But what does it mean to «die well»? What is a «good death»? There is no single, universal answer to these questions. That modern hospice movement was first promulgated largely by Christians may have hindered its development among people of other faiths for whom the «hospice philosophy» may have been hard to separate from theological commitments that they did not share. Even with respect to elements of a «good death» on which most people could probably agree — freedom from pain, resolution of personal affairs, the supportive presence of loved ones—there is a room for considerable personal variation. People differ in their willingness to face the reality of their imminent death; in their desire to talk about their feelings to friends, family, or caregivers; in how they balance pain relief against alertness; and in their willingness to tolerate increasing weakness, dependency, and uncertainty rather than trying to control the timing and manner of their death through an act of suicide or euthanasia. This variability requires health professionals to approach patients and families as individuals, in an effort to provide care that is consistent both with patient and family values and with their own conscience.

HOSPICE

I. The History of Hospice.

II. The Hospice Philosophy

Literature

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Reports, synopses, course and term paper

Palliative Medicine Approach to Caring for Patients with HIV/AIDS in Hospice.

Palliative Medicine Approach to Caring for Pediatric Patients in Hospice.

International Association of Hospice and Palliative Care.

Hospice: Good Death or Good Life.

The word «hospice» stems from the Latin word «hospitium» meaning guesthouse. It was originally used to describe a place of shelter for weary and sick travelers returning from religious pilgrimages.

Each society throughout history has evolved special ways of caring for the dying and the bereaved. For example: in old China the “death houses” offered a place for the destitute dying to stay; in New Zealand, Maori customs give practical support for the family at the time of death, and encourage the community to participate in the mourning rituals; in East Africa, wise elders give both practical and spiritual support to the dying and bereaved.

In Western Europe and North America until the 19th Century, caring for the dying and the bereaved was seen primarily as the job of the family and the church. In the last 100 years, dying has increasingly been seen as a medical event, not as a milestone in the life and history of a family.

During the 1960's, Dr. Cicely Saunders, a British physician began the modern hospice movement by establishing St. Christopher's Hospice near London. Cicely Saunders is regarded as the founder of the modern hospice movement. Dr. Saunders founded St. Christopher's in 1967, which charted new directions in both the philosophy and techniques for treatment of the terminally ill. When planning St. Christopher's, Dr Saunders stated: «The name hospice, 'a resting place for travelers or pilgrims,' was chosen because this will be something between a hospital and a home, with the skills of one and the hospitality, warmth, and the time of the other».

In the late 1960's, several students at Yale University heard about a program in England that offered special care for people diagnosed with an irreversible illness. The students invited Dr. Cicely Saunders, founder of St. Christopher's Hospice in London, to speak at Yale, and were subsequently inspired to open such a place here in the United States. Her lecture, given to medical students, nurses, social workers, and chaplains about the concept of holistic hospice care, included photos of terminally ill cancer patients and their families, showing the dramatic differences before and after the symptom control care. This lecture launched the following chain of events, which resulted in the development of hospice care as we know it today. In the United States today, over 3,000 local hospice and palliative care programs offer specialized care to people suffering from fatal illnesses, such as cancer. Good hospices are rooted in, and responsive to, the communities they serve, and to the people who live and die there. There is well-established hospice and palliative care in Canada, Australia, New Zealand, and much of Asia and Western Europe. Hospice and palliative care is now available in over 40 countries worldwide, including many less-developed nations.

World Health Organization sets standards for palliative care and pain control, calling it a «priority». But studies show that most patients still receive little or no effective palliative care, and pain is often very poorly controlled, primarily due to lack of medical knowledge, to unfounded fears of addiction, and (in less-developed nations) to shortage of opioids.

Hospice philosophy is a shift from usual medical treatments, in which health professionals strive to cure disease. Hospice services are not intended to speed up or prolong the dying process, but focus instead on relieving pain and other symptoms. Hospice caregivers are concerned with enhancing the quality of remaining life by keeping patient as alert and comfortable as possible in a familiar environment with family and friends. Hospice is a special kind of care designed to provide sensitivity and support for people in the final phase of a terminal illness. Hospice care seeks to enable patients to carry on an alert, pain-free life and to manage other symptoms so that their last days may be spent with dignity and quality at home or in a home-like setting. In accordance with the hospice philosophy, the rights of the terminally ill are the following:

The right to compassionate and confidential care.

The right to enjoy the greatest possible quality of life.

The right to die with dignity, as he or she perceives dignity.

The right to participate in the management of the remaining life span.

The right to die in familiar surroundings without pain and with loved ones present.

Hospice services generally include: 1. Basic medical care with a focus on pain and symptom control. 2. Medical supplies and equipment as needed. 3. Counseling and social support to help patient and patient's family with psychological, emotional, and spiritual issues. 4. Guidance with the difficult, but normal, issues of life completion and closure. 5. A break (respite care) for caregivers, family, and others who regularly care for the patient. 6. Volunteer support such as meal preparation or errand running.

Hospice care brings compassion, care and support to individuals and their families transitioning through life-limiting illness while providing outreach, education and expertise in grief support to the entire community. Hospice is a concept designed to help persons diagnosed with a serious illness to live more comfortably and as fully as possible. Hospice care is a special approach designed to give the same care in the final phase of life that is given in the first. At a time

when nothing more can be done to cure the disease, there is still so much that can be done for the patient. So, hospice care's goal is to relieve pain, fear and loneliness.