

Case 43

Hospice Care Movement

The Commonwealth Fund, 1974

Scott Kohler

Background. The concept of hospice care is not a new one. In fact, it has been around for centuries, if not millennia. The term “hospice” now refers to a method or place of treatment for the dying, focused on “the desire to provide some form of support—emotional, physical, or spiritual—for patients and families during terminal illness.” But hospice care once embraced a more general definition of relief. During the Crusades, for example, hospices were way stations where road-weary travelers could rest and recover. Over time, however, hospice—whether or not it was explicitly named as such—came to refer primarily to the care of terminally ill patients on the brink of death.

For centuries before they were exported to the Americas, hospices—run primarily by religious orders and existing independently of governmental authorities—were scattered around Europe, and especially the United Kingdom. Around the turn of the twentieth century, Christian clergy members in the United States began operating hospices where the sickest of patients could seek relief from pain and peace with God. These places remained over the years unaffiliated with the larger healthcare community and uninterested in the advances of modern medicine. Perhaps unsurprisingly then, they were few and far between, and by the 1930s, it was becoming more and more common for sick patients to die in hospitals and nursing homes.

As the so-called “death with dignity movement” gathered steam in the 1950s and ’60s, health care professionals around the United States began increasingly to doubt the wisdom of the conventional approach to dying: seek always to stave it off at any cost. Across the Atlantic, Dr. Cicely Saunders founded St. Christopher’s Hospice in London in 1967. Offering inpatient and home care, bereavement support for families, and a range of other services, St. Christopher’s was the most advanced example of European hospice care, and would soon become the model for the American hospice movement.

Strategy. A year before St. Christopher opened its doors, Dr. Saunders and Dr. Elizabeth Kubler-Ross, the psychiatrist who theorized the six psychic stages of dying, visited the Yale University Hospital as advocates for the death with dignity movement. The two impressed Florence Wald, dean of Yale’s Nursing School, who soon became an enthusiastic supporter of hospice care. Along with colleagues from Yale’s schools of Medicine and Divinity, Wald conducted a two-year study of existing facilities in the United States to care for the dying. During this time, Wald gathered and presided in 1967 over the landmark first meeting of the Yale Study Group, an assembly of health care professionals, religious leaders, and not-for-profit representatives that met to consider society’s response to terminal illness. As Cathy Siebold describes in *The Hospice Movement: Easing Death’s Pains*, the Group came together “to talk, even gripe, about the way terminally ill patients received aggressive treatment until they died.”⁶⁷ The YSG saw a better approach in hospice care.

In the subsequent months, Florence Wald “proceeded to contact people around the country who were interested in terminal care to see if they would like to participate in a group whose goal was to develop modern hospice programs nationally.” This new approach was controversial, and Yale University found it difficult to become too deeply involved in the work of the YSG and its successor, the International Work Group on Death, Dying, and Bereavement (IWG). However, according to McGehee Harvey and Susan Abrams, “[t]he deans of the medical, divinity, and nursing schools were very supportive of the project, as indeed was Yale’s president, Kingman E. Brewster....”⁶⁷ So, too, were the Commonwealth Fund and other private foundations. In 1973, the Fund gave Wald and her colleagues a small grant to study the feasibility of establishing in the United States a modern hospice

along the lines of St. Christopher's.

In 1974, the Group's work researching models of terminal care and gathering support for the hospice model culminated in the opening of Hospice Inc., the first modern hospice in the United States. Modeled after St. Christopher's, Hospice Inc. was incorporated in Branford, Connecticut, although its services, both outpatient and at the physical hospice, would be available to Connecticut residents around the state. Hospice Inc. would also serve as a clearinghouse for information on hospice care and a center for the growth of the hospice movement. As Hospice Inc. took shape, the Commonwealth Fund, the Van Ameringen Foundation, and the Ittleson Family Foundation gave \$100,000; \$100,000; and \$50,000 respectively for planning and the assembly of a complete home-care staff.⁶⁷³ Also in 1974, program staff of the Commonwealth Fund helped Hospice Inc. secure a \$1.5 million grant from the National Cancer Institute. Two grants of \$1 million each from the National Institutes of Health and the State of Connecticut defrayed the construction costs of Hospice Inc.'s inpatient facility.

According to Siebold, "[w]hile Saunders and Kubler-Ross were the charismatic leaders of the hospice movement, Florence Wald was its organizer."⁶⁷⁴ Wald, who had resigned from the deanship of the Yale Nursing School to support and grow the hospice model nationwide, led the way in publicizing the work of Hospice Inc. and supporting the establishment of similar institutions around the United States.

Outcomes. The hospice model of care—with its emphasis on relieving pain and offering emotional, physical, and spiritual support to dying patients and their grieving families—spread rapidly in the years after Hospice Inc. first opened. In 1975, Hospice Inc. hosted the first National Hospice Symposium, and, in the following year alone, Hospice Inc. received thirty-six separate requests for help in launching new hospices. In 1977, Hospice Inc. became a charter member of the National Hospice Organization (NHO). Prior to NHO's founding, Wald's Connecticut hospice actually had trademark rights to the term "hospice" in the United States, but it voluntarily released those rights to the new umbrella organization. In 1978, Hospice Inc. "became the first program approved for insurance reimbursement as a hospice home care service."⁶⁷⁵ Unlike the old church-run hospices, the modern hospice movement embraced the medical establishment, even if its enthusiasm was not always returned. Although much of the medical community supports the hospice movement, many health care professionals still find it hard to accept a model of care predicated on the death of its patients. But hospice care has spread nationwide all the same. The death with dignity movement came into the spotlight when the Karen Anne Quinlan case became national news in the mid-1970s.⁶⁷⁶ And by the end of that decade, "the hospice movement had achieved national renown."⁶⁷⁷ Today, there are an estimated 3,200 operating in the United States.⁶⁷⁸ These centers of care at the end of life are reimbursable by Medicare, Medicaid, and private insurance agencies.

Impact. The work of Florence Wald and her colleagues from the Yale Study Group was instrumental in founding Hospice Inc. and then in promoting its replication. According to Harvey and Abrams, "[t]he pioneering New Haven Hospice Program is still considered the model for the inpatient and home care of terminally ill patients."⁶⁷⁹ The support of the Commonwealth Fund was crucial in enabling this model to cross the Atlantic. Credit should be given to the staff of the Fund for supporting the transnational dialogue that connected the Yale Group to St. Christopher's in London. Recognizing a void in the American healthcare landscape, foundation officials searched for the right model, and, upon finding it abroad, provided crucial funding and encouragement to see it tried and proven in the United States. This, in turn, brought credibility to the hospice care movement. As Florence Wald recalls, "[o]nce the solid and prestigious foundations lent their support other ones felt more comfortable in following suit." Wald also reflects upon the decision to create Hospice Inc. as an independent entity, saying, "the then Deans of Divinity, Medicine, and Nursing [at Yale] were in agreement with the decision—but it did take the trust of Commonwealth!"⁶⁸⁰

The rise of hospice care has significantly altered the American health care landscape, and is the

most visible achievement of the death with dignity movement. The extraordinary advance of medical technology and practice over the last hundred years has given enormous momentum to the natural impulse that every disease should be treated as aggressively as possible, since a cure may be just around the corner. As Cathy Siebold points out, “[l]imited exposure to natural disaster and increased life expectancy has fostered a belief among many Americans that technology can overcome everything, including death.”⁶⁸¹ Alas, this belief is mistaken, and hospice care manifests an admission—still uncomfortable for most, and certainly in contrast to the prevailing trend—of our own mortality. As its spread throughout the United States clearly shows, however, it is an alternative which many people in their last days appreciate being offered.

Notes

671. Cathy Siebold, *The Hospice Movement: Easing Death's Pains* (New York: Twayne Publishers, 1992).
672. Harvey and Abrams, *“For the Welfare of Mankind”: The Commonwealth Fund and American Medicine* (Baltimore: Johns Hopkins University Press, 1986).
673. Ibid.
674. Siebold, *The Hospice Movement*.
675. Ibid.
676. Bert Hayslip, Jr. and Joel Leon, *Hospice Care* (Newbury Park: Sage Publications, 1992).
677. Siebold, *The Hospice Movement*.
678. Hospice of Lake Sumter website, available from <http://www.hospicels.com/faq.htm>.
679. Harvey, *For the Welfare of Mankind*.
680. Ibid.
681. Siebold, *The Hospice Movement*.