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Feature Section: Hospice Care

Hospice Care: An Overview

During World War II, Cicely Saunders, then a nurse and social worker, encountered many soldiers who were wounded and dying in great pain. She realized that pain in the dying is senseless and meaningless and that allowing people to die in pain is cruel and inhumane. After the war, she went to medical school so that she could better concentrate her efforts on the control of pain. In 1967, she founded St. Christopher’s Hospice in Sydenham, England, to provide care for dying patients. St. Christopher’s became a model for hospice care throughout the world and proved to all that patients can die painlessly, peacefully, and with dignity.

The first hospice program in the United States was started in Connecticut in 1974. Since then, giant strides have been made in the care of the terminally ill. Recent data from the National Hospice Organization show that all 50 states in our country have hospice programs, totaling approximately 1,500 programs of varying sizes and types. Medicare, Medicaid, and many private insurance providers now pay for hospice care and most states have passed legislation to ensure the quality of care. Despite this progress, however, hospices provide care to a mere 15% to 20% of all cancer patients who die each year in the United States. Thus, every year nearly 400,000 patients who die of cancer are not provided with the type of care that hospices can offer. Why are so many terminally ill patients being deprived of the freedom from pain and the physical, social, psychological, and spiritual support that hospices can provide for them and for the members of their families?

One problem is that there is inadequate involvement of the medical profession in the delivery of hospice care. Physicians are not referring their terminally ill patients for hospice care, or when they do so it is usually during the last few days of the patient’s life. Another problem is that there is a lack of a solid base of knowledge on the hospice concept of care. This is due to a dearth of scientific effort in the field of hospice care.

These two problems represent the biggest challenges confronting the hospice movement in the United States today. For more patients to be referred for hospice care, physicians need to fully understand what the hospice concept of care is all about. Physicians are trained to cure disease, to save lives, to prolong lives. They are also trained not to treat pain, because pain is a useful symptom which should guide the management of the disease. Hospice care is the opposite: if cure is no longer possible, do not try to cure; if life is coming to an end, do not try to prolong the dying process; and if there is pain, exert every effort to make the patient free from pain. This explains, in part, why physicians find it hard to refer their patients for hospice care. They tend to feel that they have failed their patients or that they have abandoned them by referring them for hospice care.

It is for the purpose of helping not only physicians but also other caregivers to understand the hospice concept of care that the Henry Ford Hospital sponsors an annual symposium on hospice care. This symposium brings to Detroit some of the most outstanding faculty from the United States to enable participants to learn from their personal expertise and thus elevate the quality of hospice care to the highest levels of excellence.

The hospice concept of care maximizes the quality of life when cure of the disease is no longer possible. The expression “there is nothing more that can be done” should refer only to curative treatment, because there is no limit to what the physician can do to make the patient as comfortable as possible and to provide the patient and the members of the family with the physical, social, psychological, and spiritual support that they all need. Hospice care enables the physician to say to the patient, “I can no longer cure you, but I will continue to care for you.” Hospice care helps the patient live until he or she dies, and thus caregivers must have the competence to address the problems of pain, loneliness, and loss of control that are unique to the dying patient.

Patient care, education, and research are the three components that any hospice program must have in order to fulfill its mission of caring for the terminally ill. As hospice caregivers become more proficient in their tasks, they will become better.
able to undertake research projects on the many aspects of hospice care. These research efforts will result in scientific publications which will gradually form the solid base of knowledge of hospice care. With the increased credibility of hospice care, even the more skeptical physicians will come to understand the advantages of referring their patients for hospice care when cure of the disease is no longer possible.

Some of the articles in this section of the Journal are based on presentations given at the First Annual Henry Ford Hospice Symposium, held in Detroit in April 1990. Two other articles, by Dr. Robert Twycross (see pp. 77-80) and Dr. Derek Doyle (see pp. 92-95), are based on presentations made at the Sixth Annual Symposium of the International Hospice Institute, held in Colorado in July 1990.

The Second Annual Henry Ford Hospice Symposium was held in Detroit in April 1991, and the Seventh Annual Symposium of the International Hospice Institute will be held in Washington, DC, at the Georgetown University Conference Center on July 10-14, 1991. Through these educational conferences and through continuing research on the hospice concept of care, we hope that physicians and other health care professionals across the United States will come to understand and value these services which provide the best quality of care to the dying when they need it most.

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