AN OVERVIEW OF THE HOSPICE MOVEMENT
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An Overview of the Hospice Movement

Introduction

Over the course of the last sixty years, many changes have been taking place in the area of terminal or end-of-life care. For most of recorded history, it was the norm for those who were dying to do so quickly, in their own home, surrounded by family (Stoddard, 1992). Those who became ill while traveling were left in the care of strangers along the way, often in places called “hospices.” But with the rapid advances in medicine in the twentieth century came a shift in the way the dying were cared for. More and more, patients were admitted to hospitals to die. Doctors became the decision-makers and patients were kept from the harsh reality of their conditions (Youk, 2005).

In the late 1940’s, a nurse in England, Cicely Saunders, began to believe there was a better way to deal with those who were nearing the end of their lives. By the 1970’s, she had become a physician and opened the first modern hospice (Clark, 2005). Soon, nurses and doctors called her to see how they, too, could develop hospice care in their communities. Her work began to transform the way dying people were cared for throughout the world. Once again there was a focus on the person’s comfort and emotional state and the family was encouraged to be active in decision-making and caregiving. Cicely Saunders’ practices continue to be a model for hospice care today and the numbers of people utilizing hospice care continue to grow. This paper will review the history of the hospice system, and will explore its effect on modern-day patients and their families.

Background

Hospice comes from the Latin word “hospes” meaning “to host a guest or stranger” (Youk, 2005). Sandol Stoddard defines it as meaning both “guest” and “host” and describes it as an interaction between people (1992). Hospice care is a part of terminal or end-of-life care. It is the interaction between a dying person and the family, the medical team, and other professionals and volunteers. It is a holistic and all-encompassing approach to caring for a person who has little or no hope of recovery and is expected to die soon. Hospice care is also in the category of palliative care, which focuses on symptom relief.

For centuries, the death of a person was a natural occurrence that happened naturally with family or community members nearby (Callanan & Kelley, 1992). In the Middle Ages, travelers who found themselves ill on their journey found host homes or “hospices.” As Christianity spread through Europe, these hospices often came in the form of monasteries or nunneries. People who were sick and dying could find rest and care in these homes with strangers (Youk, 2005).

During the twentieth century, rapid advances began to be made in the area of medicine. Vaccination programs started to take hold, Penicillin was discovered, cardiopulmonary resuscitation (CPR) was developed, and pacemakers began to be used to keep the heart’s rhythm. The technology brought with it a much longer life expectancy and high hopes for a full
restoration to health when a person became ill. The focus was switched from healing a patient to finding a cure. Physicians were encouraged to do whatever they could to prolong a person’s life, even if it was at the expense of quality of life (Youk, 2005).

During these changes, people were moved from their homes to hospitals to die with the focus being on a cure until the very end. Hospitals offered a stark contrast from the comfort of homes. The environment was sterile and families began to have to deal with visiting hours and machines. Care became passive and it was done by strangers as opposed to family. Patients were often alone and isolated. Added to the unfamiliarity of the new environment, the choices regarding medical care were transferred to the hands of strangers (Callanan & Kelley, 1992). And these strangers, the health care professionals, were reluctant to tell patients the truth about their conditions (Youk, 2005).

The Development of the Modern Hospice Concept

Many people contributed to the development and growth of the modern hospice concept. The two most prominent were Cicely Saunders and Elisabeth Kübler-Ross. The modern hospice movement can be directly attributed to their work and the work of others who followed their lead.

Cicely Saunders

In the 1940’s, Cicely Saunders was a nurse working at St. Luke’s Home for the Dying Poor in London, England. She spent time with patients there and began to think about how end-of-life care could be adjusted to better fit the patient’s and family’s needs. One patient in particular encouraged her to create her own home for terminal care. She began to take steps to make a change in this part of the medical world. She felt she could only make the necessary changes if she became a physician, which she did in 1957 at the age of 39 (Clark, 2005).

Cicely Saunders began to put her plan for a hospice into action and in 1963 she began fundraising for it. She was able to “plunder grant-giving charities in London” in order to raise the money needed. In 1967, she opened St. Christopher’s Hospice in London, England. St. Christopher’s Hospice immediately opened its doors to interested health care professionals so others could learn Cicely Saunders’ concepts of care in a hands-on manner (Youk, 2005).

Elisabeth Kübler-Ross

In 1969, a doctor named Elisabeth Kübler-Ross published a book called “On Death and Dying” after she led a study based on interviews with dying patients. In it, she identified what she called the five stages of grief and she took a close look at how dying patients were treated and how they felt during the process (Kübler-Ross, 1969). She devoted her life to the cause of bringing talk of death and end-of-life care into the open and often spoke about dying people, their needs, and their experiences. Her work, along with the ongoing work of Cicely Saunders, began to bring talk of death and dying out into the open where it had previously taken place behind closed doors.
Expansion of the Modern Hospice Concept

The modern hospice concept began to catch the attention of health care professionals throughout the world. Many medical professionals began to get in contact with Cicely Saunders to find out more about her hospice home and her ideas surrounding the care of her patients.

Florence Wald

Florence Wald was Dean at the Yale School of Nursing. Inspired after hearing Cicely Saunders speak on the subject of death and dying, she traveled to London in 1965 to learn what she could about the compassionate care of the dying at St. Christopher’s Hospice (Youk, 2005). She brought what she had learned back to New Haven, Connecticut, and opened the first hospice in America based on Cicely Saunders’ practices and principles in 1974 (Baird & Rosenbaum, 2003).

Soon after, other hospices began to open including one in Montreal in 1975 and another in California in 1979 (Youk, 2005). There had been only a handful of homes for the dying in 1967, but now the concept of palliative care and dying with dignity had begun to spread rapidly.

About Hospice

Hospice is a “philosophy or approach to care as opposed to a place” (“About hospice,” 2011). It attempts to serve the dying person and their family wherever the need is, most often in the person’s home. Hospice also provides care in a facility. The goal is to keep the patient where they are comfortable if medically possible. Hospice becomes involved when called in by the family, usually when the patient is determined to have six months or less to live. The average length of stay was 69 days in 2009 (“NHPCO Facts,” 2010).

Hospice care in the United States relied on grants and donations until the Medicare Hospice benefit was enacted in 1986 and Medicare and Medicaid continue to provide the main source of funding for hospice care in the United States. In the United Kingdom, hospice services are offered at no cost to the patient or family (Baird & Rosenbaum, 2003).

Goals

The goals of hospice are to honor the patient’s life, attempt to provide a higher quality of life, and help the person die with dignity (Baird & Rosenbaum, 2003). The basic philosophy is well-stated by Cicely Saunders when she said, “You matter because you’re you. You matter to the last moment of your life, and we will do all we can to not only help you die peacefully, but also live until you die” (as cited in Stoddard, 1992, p. 109). She wanted the patient’s life to be honored and them to have a say in their treatment and the dying process.

Hospice care views death as a natural process and values the patient’s and family’s goals, values, plans, and opinions. It attempts to support the patient and family by helping meet their physical, spiritual, emotional, and social needs. The patient is in control of the choices regarding
their care and treatment. It also attempts to alleviate troublesome symptoms that come along with the disease or process of death so that the patient can be as comfortable as possible (Baird & Rosenbaum, 2003).

**Services**

Some of the core services hospice provides are nursing and physician services, counseling and social work, spiritual care, and volunteer services. Nursing provides help in caring for the patient and instruction for other caregivers, including family. Nurses visit and are also available on an on-call basis. Physicians provide medication for pain and symptom relief along with medical oversight and testing. Counseling is available to the individual during the process, and to the family before and after the patient’s death. Spiritual care is available to assist in the spiritual aspects of the dying and grief processes. Chaplains are often part of the care team. Volunteers provide help with a wide range of services from grocery shopping to playing instruments to just sitting with the patient or family (Carlson et al., 2007).

**Challenges**

Although hospice offers a wide range of help to the individual and their family and its use is becoming widespread, it still remains a mystery to many. Because it is associated with death, people tend to avoid talking about it. To some, it means giving up hope (Baird & Rosenbaum, 2003). Hospice is often associated with euthanasia and the right-to-die fight, likely because of its focus on symptom-relief as opposed to cure.

Other challenges include meeting a patient’s or family’s high expectations and keeping hospice being accessible to those who need its services. There are differences in accessibility and perception based on race, income, and education (Vig et al., 2010). The geographic locations of hospices also provide an obstacle for some (Carlson et al., 2010).

**Future**

Despite the many challenges, hospice care continues to grow. According to the National Hospice and Palliative Care Organization (“NHPCO Facts,” 2010), an estimated 41.6 percent of deaths were under the care of hospice in 2009. From 1999 to 2006, the rates of nursing homes using hospice services rose from 14% to 33% (Miller et al., 2010). With a large aging population of baby boomers in the United States, and with those involved in hospice attempting to get the word out about its services, numbers are expected to continue to rise. An estimated 1,560,000 people who died in the United States in 2009 were served by hospice compared with just 100,000 in 1984 (See Figure 1).
Cicely Saunders brought new ideas about hospice care from her experience at St. Luke’s Home for the Dying Poor, while the writings of Elizabeth Kübler-Ross brought talk of death into the open. Both women’s ideas, along with many other forces, combined to start a change in the way the dying were cared for. Health care professionals from around the world traveled to Cicely Saunders’ creation – St Christopher’s Hospice – to learn her techniques and practices. Those professionals then brought what they had learned to their own communities and the ideas began to take hold. The idea of helping others to have a more peaceful and painless death became something many people strived for.

While hospice care faces challenges in the future, its growth shows no signs of slowing down. Families are taking advantage of the shift back from passive end-of-life care in hospitals to the holistic and palliative care that hospice provides. While mystery still surrounds hospice, many are finding value in the approach that views death as a natural process and gives physical, emotional, social, and spiritual support to both the family and the dying person. With a large aging population, hospice care continues to evolve to try to meet the needs of people who are dying and the people who care for them.

Figure 1. Patients Served by Hospice in the U.S.: 1984 – 2009
(“Patients Served,” 2009)
References


