See this page in the course material.

Learning Outcomes

- Explain the philosophy and practice of palliative care
- Describe hospice care
- Summarize Dame Cicely Saunders' writings about total pain of the dying
- Differentiate attitudes toward hospice care based on race and ethnicity

Palliative Care

Palliative care is an interdisciplinary approach to specialized medical and nursing care for people with life-limiting illnesses. It focuses on providing relief from the symptoms, pain, physical stress, and mental stress at any stage of illness, with a goal of improving the quality of life for both the person and their family. Doctors who specialize in palliative care have had training tailored to helping patients and their family members cope with the reality of the impending death and make plans for what will happen after.[1]

Palliative care is provided by a team of physicians, nurses, physiotherapists, occupational therapists, speech-language pathologists, and other health professionals who work together with the primary care physician and referred specialists or other hospital or hospice staff to provide additional support to the patient. It is appropriate at any age and at any stage in a serious illness and can be provided as the main goal of care or along with curative treatment. Although it is an important part of end-of-life care, it is not limited to that stage. Palliative care can be provided across multiple settings including in hospitals, at home, as part of community palliative care programs, and in skilled nursing facilities. Interdisciplinary palliative care teams work with people and their families to clarify goals of care and provide symptom management, psychosocial, and spiritual support.

Hospice

In many other countries, no distinction is made between palliative care and hospice, but in the United States, the terms have different meanings and usages. They both share similar goals of providing symptom relief and pain management, but **hospice care** is a type of care involving palliation without curative intent. Usually, it is used for people with no further options for curing their disease or ~~in~~ people who have decided not to pursue further options that are arduous, likely to cause more symptoms, and not likely to succeed.The biggest difference between hospice and palliative care is the type of illness people have, where they are in their illness especially related to prognosis, and their goals/wishes regarding curative treatment. Hospice care under the Medicare Hospice Benefit requires that two physicians certify that a person has less than six months to live if the disease follows its usual course. This does not mean, though, that if a person is still living after six months in hospice he or she will be discharged from the

service.

Watch It

Watch this video to better understand the setting, circumstances, and services associated with hospice care.

See this interactive in the course material.

You can view the transcript for “Understanding Hospice Care” here (opens in new window).

Hospice care involves caring for dying patients by helping them be as free from pain as possible, providing them with assistance to complete wills and other arrangements for their survivors, giving them social support through the psychological stages of loss, and helping family members cope with the dying process, grief, and bereavement. It focuses on five topics: communication, collaboration, compassionate caring, comfort, and cultural (spiritual) care. Most hospice care does not include medical treatment of disease or resuscitation although some programs administer curative care as well. The patient is allowed to go through the dying process without invasive treatments. Family members who have agreed to put their loved one on hospice may become anxious when the patient begins to experience death. They may believe that feeding or breathing tubes will sustain life and want to change their decision. Hospice workers try to inform the family of what to expect and reassure them that much of what they see is a normal part of the dying process.

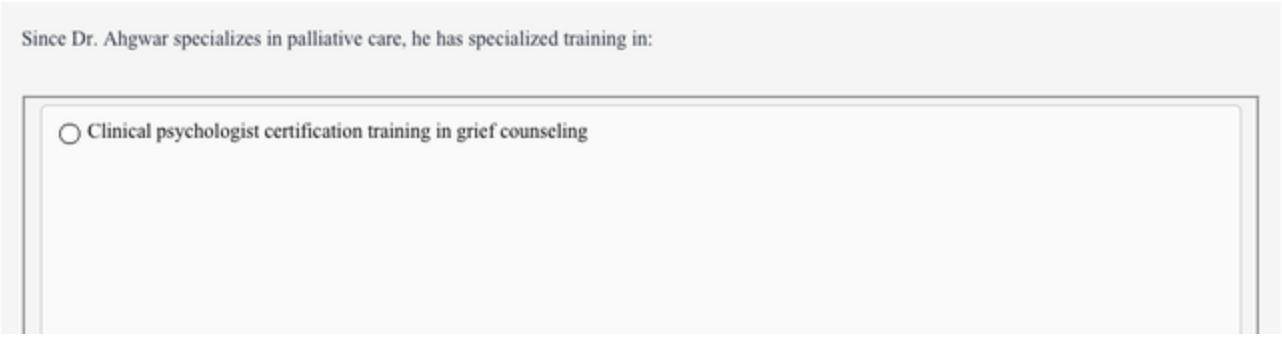
Watch It

One aspect of palliative and hospice care is helping dying individuals and their families understand what is happening, and what it may imply for their lives. The following video provides an example of palliative care in a hospital setting.

Video Link

You can view the transcript for “How Doctors Tell Patients They’re Dying | Being Mortal | FRONTLINE” here (opens in new window).

Try It



See this interactive in the course material.

See this interactive in the course material.

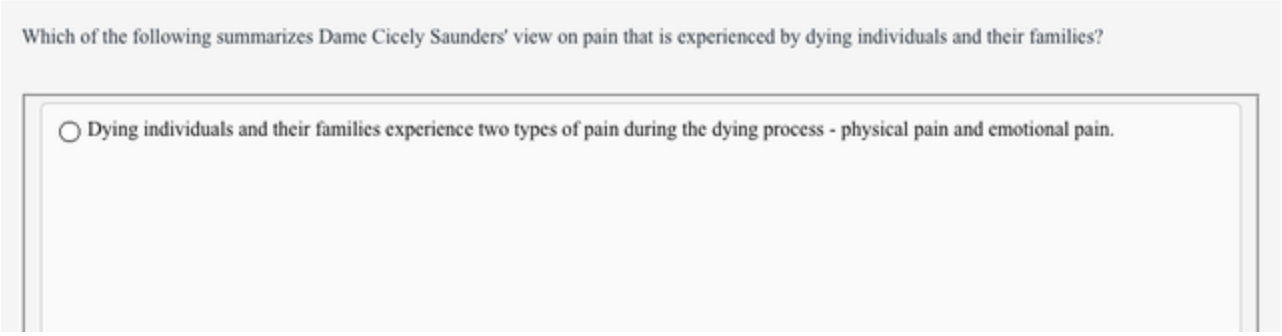
The History of Hospice

Dame Cicely Saunders was a British registered nurse whose chronic health problems had forced her to pursue a career in medical social work. The relationship she developed with a dying Polish refugee helped solidify her ideas that terminally ill patients needed compassionate care to help address their fears and concerns as well as palliative comfort for physical symptoms. After the refugee's death, Saunders began volunteering at St Luke's Home for the Dying Poor, where a physician told her that she could best influence the treatment of the terminally ill as a physician. Saunders entered medical school while continuing her volunteer work at St. Joseph's. When she achieved her degree in 1957, she took a position there.

Saunders emphasized focusing on the patient rather than the disease and introduced the notion of 'total pain', which included psychological, spiritual, emotional, intellectual, and interpersonal aspects of pain, the physical aspects, and even financial and bureaucratic aspects. This focus on the broad effects of death on dying individuals and their families has provided the foundation for modern day practices related to hospice care services.[2] Saunders experimented with a wide range of opioids for controlling physical pain but also considered the needs of the patient's family.

Saunders disseminated her philosophy internationally in a series of tours of the United States that began in 1963. In 1967, Saunders opened St. Christopher's Hospice. Florence Wald, the Dean of Yale School of Nursing who had heard Saunders speak in America, spent a month working with Saunders there in 1969 before bringing the principles of modern hospice care back to the United States, establishing Hospice, Inc. in 1971. Another early hospice program in the United States, Alive Hospice, was founded in Nashville, Tennessee on November 14, 1975. By 1977 the National Hospice Organization had been formed.

Try It



See this interactive in the course material.

Hospice Care in Practice

The early established hospices were independently operated and dedicated to giving patients as much control over their own death process as possible. Today, it is estimated that over 40 million individuals require palliative care, with over 78% of them being of low-income status or living in low-income countries. [3] It is also estimated, however, that less than 14% of these individuals receive it. This gap is created by restrictive regulatory laws regarding controlled substance medications for pain management, as well as a general lack of adequate training in regards to palliative care within the health professional community. Although hospice care has become more widespread, these new programs are subjected to more rigorous insurance guidelines that dictate the types and amounts of medications used, length of stay, and types of patients who are eligible to receive hospice care. Thus, more patients are being served, but providers have less control over the services they provide, and lengths of stay are more limited. Patients receive palliative care in hospitals and in their homes.

The majority of patients on hospice are cancer patients and they typically do not enter hospice until the last few weeks prior to death. The average length of stay is less than 30 days and many patients are on hospice for less than a week. Oftentimes medications are rubbed into the skin or given in drop form under the tongue to relieve the discomfort of swallowing pills or receiving injections. A hospice care team includes a chaplain as well as nurses and grief counselors to assist spiritual needs in addition to physical ones. When hospice is administered at home, family members may also be part, and sometimes the biggest part, of the care team. Certainly, being in familiar surroundings is preferable to dying in an unfamiliar place. But about 60 to 70 percent of people die in hospitals and another 16 percent die in institutions such as

nursing homes. Most hospice programs serve people over 65; few programs are available for terminally ill children. [4]

Hospice care focuses on alleviating physical pain and providing spiritual guidance. Those suffering from Alzheimer's also experience intellectual pain and frustration as they lose their ability to remember and recognize others. Depression, anger, and frustration are elements of emotional pain, and family members can have tensions that a social worker or clergy member may be able to help resolve. Many patients are concerned with the financial burden their care will create for family members. And bureaucratic pain is also suffered while trying to submit bills and get information about health care benefits or to complete requirements for other legal matters. All of these concerns can be addressed by hospice care teams.

The Hospice Foundation of America notes that not all racial and ethnic groups feel the same way about hospice care. [5] Certain groups may believe that medical treatment should be pursued on behalf of an ill relative as long as possible and that only God can decide when a person dies. Others may feel very uncomfortable discussing issues of death or being near the deceased family member's body. The view that hospice care should always be used is not held by everyone and health care providers need to be sensitive to the wishes and beliefs of those they serve. Similarly, the population of individuals using hospice services is not divided evenly by race. Approximately 81% of hospice patients are White, while 8.7% are African American, 8.7% are multiracial, 1.9% are Pacific Islander, and only 0.2% are Native American. [6]

Watch It

The following video from the National Hospice and Palliative Care Organization discusses some of its goals regarding the increase in hospice care availability.

See this interactive in the course material.

You can view the transcript for "NHF Gala 2015 Final Video" here (opens in new window).

Try It

See this interactive in the course material.

Glossary

hospice: a type of care involving palliation without curative intent. Usually, it is used for people with no further options for curing their disease or people who have decided not to pursue further options that are arduous, likely to cause more symptoms, and not likely to succeed. palliative care: an interdisciplinary approach to specialized medical and nursing care for people with life-limiting illnesses. It focuses on providing relief from the symptoms, pain, physical stress, and mental stress at any stage of illness, with a goal of improving the quality of life for both the person and their family.

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6. Campbell, C., Baernholdt, M., Yan, G., Hinton, I. D., & Lewis, E. (2014). Racial/ethnic perspectives on the quality of hospice care. American Journal of Palliative Care, 30(4), 347-353.

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