Abstract

Terminally ill patients and their families have specific spiritual, social, psychological and physical needs. Although these needs are mostly universal, understanding of cultural preferences and variables is important for defining the most appropriate type of care. Hospice is recognized as a holistic health service designed to provide palliative care for dying persons. Interdisciplinary team and volunteers serving the dying patient and family develop the special mission of hospice.

Understanding the Hospice Concept

Hospice care is a holistic health service designed to meet the spiritual, social, psychological, and physical needs of a terminally ill individual. Terminally ill patients can be defined as someone whose disease is non-responsive to curative treatment measures and aggressive medical protocol are ceased. Unlike most health services, hospice fosters palliative care to provide appropriate comfort and support for dying persons. Palliative care “emphasizes relief from pain and other distressing symptoms, integrates the physical, psychological, and spiritual aspects of patients care, offers a support system to help the patient live as actively as possible until death and a support system to help the family cope during the patient’s illness and in their own bereavement” (World Health Organization, 1990). Hospice care can be referred to as the portion of palliative care provided in the home or other supportive residential environment. Hospice “provides support and care for persons in the last phases of incurable disease… and recognizes dying as part of the normal process of living focusing on maintaining the quality of remaining life. Hospice exists in the hope and belief that through appropriate care, and the promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death (National Hospice Organization, 1993). Opioids such as morphine are the common medication used to control pain. One of the goals of hospice is to initiate the understanding for the patient and family members that the dying process has begun and extend the grieving period while the terminally ill patient is alive to reduce the stress of the family upon time of death.

The three (3) main criteria used in the United States for the appropriateness of hospice care is: 1) that the patient has been determined by the attending physician as having a non-curable, terminal disease where aggressive, curative treatment is not progressive, 2) the terminally ill patient is determined to have six (6) months or less to live, and 3) the patient or guardian has made an informed decision about utilizing hospice. A guardian is a person who is legally responsible for making decisions for another person who is deemed by the court to be unable to make competent, sound decisions.

Dying as a Normal Life Process (Acceptance Cycle)

In many cultures death any dying is often hidden and not discussed by the patient or among family, friends, and medical staff. Research and study in the area of death and dying took a substantial step during the 1960’s when Dr. Elizabeth Kubler-Ross investigated
dying patients. Building on the early work of Cicely Saunders, Dr. Kubler-Ross found that physicians and nurses were not susceptible to studying dying patients because it was viewed as morbid and inappropriate. Her persistence in this field led to the famous publication *On Death and Dying* in 1969 which created a theoretical framework describing the psychological of the dying patient as she perceived them. Kubler-Ross (1969) identified five stages:

1) Denial - This expression hinders belief by the patient and that the diagnosis must be a mistake;

2) Anger - The diagnosis is confirmed with the patient and he/she begins to ask why this happened to me. Emotional outrage and unfairness are typical expressions;

3) Bargaining - The patient understands the disease is present but often does not believe other alternatives are available;

4) Depression - Reactive depression is when the patient responds to past and present losses. Preparatory depression is anticipating future losses to come;

5) Acceptance - Often described as “almost void of all feelings” and the patient is waiting the inevitable.

Once death and dying is perceived as normal by society, medical professionals, family members, and ultimately the terminally ill patient, support persons can begin to understand the needs of the dying patient. Hospice care can play a vital role in caring for the patient and provide support for family members once the needs are identified.

### Understanding the Needs of the Dying Patient

With support from the National Health Service in London, Cicely Saunders created the St. Christopher’s Hospice in Sydenham on the outskirts of London in 1967. Her methodology was practical, patient-centered care using seven (7) fundamental principles focusing on the interdisciplinary needs of cancer patients. Saunders (1967) recognized these principles as follows:

1) Death must be accepted

2) The patient’s total care must be managed by a skilled interdisciplinary team whose team members communicate regularly with one another,

3) The common symptoms of terminal disease, especially the palliation of pain in all aspects, need to be controlled effectively,

4) The patient and family as a single unit of care must be identified,

5) An active home care program should be implemented,

6) An active program of bereavement care for the family after the death of the patient must be provided, and

7) Research and education must be ongoing.

It is essential to understand the needs of the dying patient and the family. Once the need are identified, appropriate training and education for staff and volunteers can be provided. Ongoing research and scholarship in the field of hospice care is crucial. Although the seven principles identified are universal, cultural preferences and variables will play a role in defining the most appropriate type of care.

### Systemic Development of Hospice: Six Fundamental Components

The specific location, culture, and community needs will dictate the type of hospice program developed. In a later section various models of hospice will be discussed. The type of program will also evolve during the systemic planning cycle. Planning hospice services involves six (6) fundamental components. Lamb (1985) identifies these components.

#### Community Support

- General Public
- Physicians
- Health and human services professionals
- Clergy and civic leaders
- Community assessment

#### Marketing

- Target population
- Service needs
- Demand for service
- Organizational resources
- Community resources

#### Fiscal

- Reimbursement
- Starting costs
Community support is the most important element in the systemic planning process. Lamb (1985) defines community support for hospice as "the widespread belief that hospice is a viable health care option warranting promotion and development." Fostering community support happens in numerous ways. Personal experience with close friends and relatives who suffered with a terminal illness often develops support for hospice care. Continuous education to the general public through community programs and pamphlets create awareness. Focused educational training and development to foster a holistic team approach for physicians and other health professionals will enhance collaboration and hospice support. Integration of hospice services along the continuum of health services creates awareness with other health organizations regarding the importance and mission of hospice care. Lamb (1985) suggests that support by health care professionals, public policymakers, and the community determines the success of hospice care.

**Interdisciplinary Team**

Members of the team should include the hospice medical director, nurses, social workers, bereavement counselors, and volunteers. The role of the medical director is to determine medical necessity for the patient by certifying a terminal illness is present. Continuous assessments are made by the medical director on each patient. Some additional responsibilities include support for primary care when the attending physician is not available, pain and symptom management knowledge, and the ability to work comfortably with dying patients. Strong emotional awareness and empathy are also critical. The medical director must communicate effectively to support the attending physician and develop a pleasant working environment for the hospice team members.

The nursing staff provides most of the direct patient care. In addition to general patient care, nurses must be trained in the area of pain and symptom management including aspects of emotional, psychological, and spiritual. Since most direct contact with the patient is with the nurse, close bonds are often made. The patient often looks to the nursing staff for assurance, support, and a friend.

Ensuring that the overall holistic needs of the patient and family members are provided is essential. Along with guidance for patient care coordination, financial assistance, and legal concerns, medical social workers often deal with any unexpected problems or issues that may arise. Special requests for therapies such as art and music are coordinated by the social worker. This staff personnel is the primary contact for family members.

Bereavement counselors provide support to family members before and after the terminally ill patient has died. The primary goal of the counselor is to help support the grieving process for the family members at an early stage of the hospice care. This usually establishes a more soothing response from the family upon time of death because the acceptance and realization process is ongoing. The counselor emotionally and psychologically helps prepare the family for the patient's death. Services are usually provided to family members up to one year after a loved one's death.

Volunteers serve many functions in a hospice setting. Many of the volunteers have personal experience with loved one's who have died in a hospice settings and offer experience with death, emotional support, and friendship. A sense of understanding and empathy is provided to family members by hospice
volunteers. Volunteers often provide direct hands-on service, recreational activities within the hospice setting, and spiritual gatherings. Volunteer training is provided for interested individuals.

The interdisciplinary team may include a wide variety of other staff to include a volunteer coordinator, activities director, and spiritual leader. The focus of the team in the hospice setting is to support not only the patient and family members, but each other. Hospice care support groups for staff should be provided on a regular basis. The cohesiveness of the hospice team is a critical factor in providing quality hospice services. Support for each team member and continuing education is significant in developing a successful service.

Models of Hospice

The model of hospice care depends on the service location, the population at interest, payment methodologies, public policy, and other key variables. Paradis (1985) note five (5) predominant models of hospice care:

1) **Free standing hospice** - A private or non-profit entity separate from a health system serving only hospice services
2) **Hospital-affiliated, free standing hospital** - A separate hospice location apart from the parent hospital
3) **Hospital-based hospice** - In-patient hospice program within the hospital
4) **Hospice within an extended-care facility or nursing home** - Visiting hospice staff serving patients in long term care settings, and
5) **Home care program** - Visiting hospice staff to serve patients and families in the homes

Reference to the six (6) fundamental components of community support, organization design, marketing, public policy/regulation, underpinnings, and fiscal resources will determine the type of hospice model most appropriate for a specific community. Hospice programs are generally localized programs building from the needs of the immediate community. For example, a home care hospice program may be more appropriate in a village or town on the outskirts of town whereas a combination of inpatient, home care, and free-standing for a large city may be more successful. Cultural, ethical, and religious values will also predict the level and type of services provided. Community needs and assessment will help establish the guidelines for developing and implementing a successful program.

**International Hospice Care**

The World Health Organization (WHO) recommends a centrally located, high-level center for countries beginning hospice programs. This will identify hospice care as a separate service from common curative medical approaches to disease. Stjernsward (1997) cites WHO’s recommendation that countries interested in developing hospice care should establish three (3) specific measures:

1) **Governmental policy**
2) **Education, and**
3) **Drug Availability**

Stjernsward (1997) suggests that all three areas must be established stating an example that “the establishment of a national policy on relieving cancer pain and success in educating the public, healthcare professionals, and policymakers will be inadequate if the necessary drugs (especially the opioid analgesics) are not available for the patients.” Although pain control medications may be available, access by professionals may be limited due to strict public policy. Many progressive steps towards national cancer relief programs are developing. Stjernsward (1997) notes that Malaysia has changed its laws to make morphine more accessible, Zimbabwe has developed its own national cancer control program producing controlled oral morphine tablets, and the province of Catalanian, Spain succeeded in extending palliative care to over 40% of its terminal cases in a short time through clear and rational policy changes.

Lack of prevention, early detection, and effective treatment in the early stages of cancer are common traits in many countries. Death and dying is often hidden and not discussed due to religious, cultural, and social norms. The terminally ill patient is often cared for in the home by family members. The strong family ties, a common characteristic in developing countries, can be a useful mechanism in fostering community support and awareness for hospice care. Ongoing
research in the area of hospice, death, and dying is advancing worldwide. Although barriers for developing hospice vary from country, the fundamental principles of hospice will nurture success.

Conclusion
Providing a holistic health service designed to meet the spiritual, social, psychological, and physical needs of a terminally ill individual creates a dignified and graceful experience for patients and family members. Developing hospice criteria and guidelines is essential to control and monitor appropriate use of palliative medicine. Accreditation standards and surveillance are important methods to assure the success of hospice care. An interdisciplinary team of professionals and volunteers committed to serving the needs of the dying patient and family develops the special mission of hospice. The hospice approach to serving the needs of the terminally ill will not only dignify the human spirit for all those involved, but will allow loved ones and staff to bond as a community to celebrate life, death, and dying.

References