History of Hospice

The concept originated in Europe, where hospices were resting places for travelers.

Monks and nuns believed that service to one’s neighbor was a sign of love and dedication to God.

They were places of refuge for the poor, the sick, and travelers on religious journeys.

They provided food, shelter, and care to ill guests until they were strong enough to continue their journey or they died.

History of Hospice

The idea of hospice was renewed in the 1960s in London, when Dame Cicely Saunders, a nurse and physician, realized that a different kind of care was needed for the terminally ill.

She then devoted her life to improving pain management and symptom control for people who were dying.

The philosophy of hospice migrated to the United States in the early 1970s, with the first hospice program opening in Connecticut in 1971.

Palliative versus Curative Care

Hospice care is appropriate when active treatment is no longer effective and supportive measures are needed to assist the terminally ill patient through the dying process.

It offers the patient a supported and safe passage from life to death in a way that preserves dignity and important relationships.

Death and dying become realities affecting the family roles, lifestyle patterns, and future goals of the patient and family.

Figure 40-1
• Curative treatment is aggressive care in which the goal and intent are to cure the disease and to prolong life at all cost.

• Palliative care is not curative in nature but is designed to relieve pain and distress and to control symptoms of the disease.

• Quality, and not quantity, of life is emphasized with hospice care.

• Palliative care is not giving up hope; it is full of hope of a good, fulfilling life.

• Criteria for Admission

• The attending physician must certify that the patient’s illness is terminal and that the patient has a prognosis of 6 months or less to live.

• The patient must be willing to forego any further curative treatment and be willing to seek only palliative care.

• The patient and caregiver must understand and agree that the care will be planned according to comfort and that life-support measures may not necessarily be performed.

• The patient and caregiver must understand the prognosis and be willing to participate in the planning of the care.

• Goals of Hospice

• Controlling or alleviating the patient’s symptoms

• Allowing the patient and caregiver to be involved in the decisions regarding the plan of care

• Encouraging the patient and caregiver to live life to the fullest

• Providing continuous support to maintain patient/family confidences and reassurances to achieve these goals

• Educating and supporting the primary caregiver in the home setting that the patient chooses

• Interdisciplinary Team

• Multiprofessional health team works together in caring for the terminally ill patient.
• They develop and supervise the plan of care in conjunction with all of those involved with the care.

• The interdisciplinary team considers all aspects of the family unit, providing support both to the dying patient and to the caregiver.

• The family is included in all decisions and care planning.

Interdisciplinary Team

Medical Director
  ▪ A doctor of medicine or osteopathy
  ▪ Assumes overall responsibility for the medical component of the hospice patient’s care program
  ▪ Acts as a consultant for the attending physician
  ▪ Is a mediator between the interdisciplinary team and the attending physician

Interdisciplinary Team

Nurse Coordinator
  ▪ Registered nurse who coordinates the implementation of the plan of care for each patient
  ▪ May perform the initial assessment, admit the patient to the hospice program, and develop the plan of care along with the interdisciplinary team
  ▪ Ensures the plan of care is being followed, coordinates the assignments of the hospice nurses and aides, facilitates meetings, and determines the methods of payments

Interdisciplinary Team

Social Worker
  ▪ Evaluates and assess the psychosocial needs of the patient
  ▪ Assists with community resources and filing insurance papers
  ▪ Supports the patient and caregiver with emotional and grief issues
  ▪ Assists with counseling when communication difficulties are present

Interdisciplinary Team

Spiritual Coordinator
- Must have a seminary degree, but can be affiliated with any church
- Is the liaison between the spiritual community and the interdisciplinary team
- Assists with the spiritual assessment of the patient and, in keeping with the patients' and families' beliefs, develops the plan of care regarding spiritual matters
- Assists the patient and caregiver to cope with fears and uncertainty
- Assists with funeral planning and performing funeral services

• Interdisciplinary Team

• Volunteer Coordinator
  - Must have experience in volunteer work
  - Assess the needs of the patient and caregiver for volunteer services
  - Provides companionship, caregiver relief through respite care, and emotional support
  - Volunteers may read to the patient, sit with the patient, or do grocery shopping or yard work.

• Interdisciplinary Team

• Bereavement Coordinator
  - Professional who has experience in dealing with grief issues
  - Assesses the patient and caregiver at admission to the hospice program and identifies risk factors that may be of concern following the death of the patient
  - Follows the plan of care for the bereaved caregiver for at least a year following the death
  - May also provide counseling or refer to other counseling resources

• Interdisciplinary Team

• Hospice Pharmacist
  - Must be a licensed pharmacist and available for consultation on the drugs the hospice patient may be taking
  - Evaluates for drug-drug or drug-food interactions, appropriate drug doses, and correct administration times and routes

• Interdisciplinary Team

• Dietitian Consultant
Licensed medical nutritional therapists (LMNTs) are available for consultations and for diet counseling.

Nutritional assessment is done at admission by the hospice nurse; if nutritional problems are noted, the patient may be referred to the LMNT.

LMNTs assist with educating the caregiver regarding nutritional issues in end-stage disease.

- Interdisciplinary Team
  - Hospice Aide
    - Certified nurse assistant who is supervised by the hospice nurse
    - Follows the plan of care developed by the interdisciplinary team
    - Assists the patient with bathing and personal care
    - May also assist the patient/caregiver with light housekeeping services

- Interdisciplinary Team

- Other Service Providers
  - Physical therapist
  - Speech-language pathologist
  - Occupation therapist
  - Not for rehabilitative services but to assist with improving the quality of life and care for the patient and caregiver

- Palliative Care

- Pain
  - The most dreaded and feared symptom
  - Priority for symptom management
  - Can be excruciating, constant, and terrifying
  - Pain assessment
    - Evaluation of the factors that alleviate or exacerbate a patient’s pain
    - Should be ongoing

- Palliative Care

- Pain (continued)
Somatic pain
- Arises from the musculoskeletal system
- Described as aching, stabbing, or throbbing
- Nonsteroidal anti-inflammatory drugs, nonopioid drugs, or opioid drugs used

Visceral pain
- Originates from the internal organs
- Described as cramping, pressure, dull, or squeezing
- Anticholinergic medications alone or as adjuvants

Neuropathic pain
- Initiated from the nerves and nervous system
- Tingling, burning, or shooting pains
- Anticonvulsants may be given as an adjuvant to assist with pain control.

Routes
- Oral, sublingual, subcutaneous, parenteral, rectal, or topical

Nursing interventions and patient teaching
- The nurse’s role is to focus on the effectiveness of the plan to ensure that the symptoms are being well controlled.
- The nurse must consistently assess and reassess the pain and symptoms to ensure that they are managed.
- Educate the patient and caregiver in the appropriate administration, scheduling, and effects of the medication.
- Pain assessment scales should be utilized.

Pain assessment scales should be utilized.

Nursa and Vomiting
Must be assessed as to their cause, with the cause being removed if at all possible.

- Nausea can result from chemotherapy side effects, obstruction, tumor, uncontrolled pain, constipation, and even food smells.
- Sometimes drugs used to control pain cause nausea; it is recommended that antiemetics be given with the narcotic analgesic.

- Palliative Care

- Nausea and Vomiting (continued)
  - Nursing interventions and patient teaching
    - Educate the patient and caregiver regarding the cause or prevention of nausea and vomiting.
    - Encourage the patient to take the antiemetics 30 minutes before meals and at bedtime.
    - Eating slowly and in a pleasant atmosphere is a good way to control nausea.
    - Patients should not be forced to eat or drink if they have no desire.

- Palliative Care

- Constipation
  - This is one of the most common problems of the terminally ill patient.
  - Factors that contribute to constipation are poor dietary intake, poor fluid intake, use of opioids for pain control, and decrease in physical activity.
  - A rectal exam may be necessary to check for an impaction along with manual removal of stool.
  - Fleet enema helps soften and dissolve a hard impaction.

- Palliative Care

- Constipation (continued)
  - Nursing interventions and patient teaching
    - Educate the patient and caregiver on the following
      - A decrease in oral intake will also decrease the amount of stool expelled.
      - Even though a patient does not have oral intake, bowel movements may still be possible.
      - Opioids can cause constipation, so laxatives must be given.
      - Comfort is the all-important factor.
Anorexia and Malnutrition

- Poor appetite may be caused by nausea, vomiting, constipation, dysphagia, stomatitis, tumor invasion, general deterioration of the body, depression, or infections.
- Odors of food cooking, inability to tolerate sweet foods, or a bitter taste in the mouth also contributes to the problem.
- Cachexia is malnutrition marked by weakness and emaciation.

Nursing interventions and patient teaching

- Nutritional assessments must be completed routinely and applied to the hospice plan of care.
- Assess and treat causes such as nausea and vomiting.
- If related to infection or stomatitis, good oral hygiene is important.
- If the odor of food causes anorexia, the patient should not be in the kitchen during meal preparation.
- High-protein supplements are helpful.

Dyspnea or Air Hunger

- Dyspnea can be caused by a variety of conditions such as heart failure, dysrhythmias, infection, ascites, or tumor growth.
- Air hunger may be caused by tumor pressure, fluid and electrolyte imbalance, or anemia.
- It may be relieved by oxygen, morphine, or bronchodilators.
- Often 24 to 48 hours before death, the patient exhibits the “death rattle,” which is an accumulation of mucus and fluids in the posterior pharynx.

Nursing interventions and patient teaching
• Main focus is on relieving anxiety and supporting the patient and caregiver.
• Educate on positioning, use of a fan to circulate air, use of morphine to decrease respiratory effort, use of tranquilizers to ease anxiety, and maintaining good oral hygiene.
• Suctioning should occur only if the patient is choking and unable to recover.

Palliative Care

Psychosocial and Spiritual Issues
■ Concerns must always be respected, and the patient's wishes are met if at all possible.
■ Patients may question their faiths and beliefs or may look to find support that they have never had when they are confronted with a terminal illness.
■ Symptoms such as depression, the need to suffer, bitterness, anger, hallucinations, or dreams of fire may be indicative of unmet spiritual needs.

Palliative Care

Psychosocial and Spiritual Issues (continued)
■ Nursing interventions and patient teaching
  ■ The spiritual coordinator or the nurse does the spiritual assessment and must be nonjudgmental and accepting of the patient's and caregiver's spiritual beliefs.
  ■ The social worker may assist in relationships between the patient and caregiver and provide counseling to resolve conflict.

Palliative Care

Other Common Signs and Symptoms
■ Weight loss
■ Dehydration
■ Weakness
■ Risk for skin impairment
■ Depression
■ Sleeplessness and insomnia

Palliative Care
Other Common Signs and Symptoms (continued)

Nursing interventions and patient teaching

- Teach the basics of good skin care.
- Cleanliness promoted by bathing can be refreshing as well as therapeutic.
- Inspect skin frequently and keep it dry and clean.
- Egg-crate mattress and elbow protectors can cushion bony areas.
- Provide information regarding home safety.
- Listen and provide emotional support.

Patient and Caregiver Teaching

- The approach taken in all matters affecting the patient and caregiver is as honest and straightforward as possible.
- It is thought that the fear of the unknown is always greater than the fear of the known.
- Educating the caregiver in symptom management, hands-on care of the patient, caring for body functions, and teaching regarding the signs and symptoms of approaching death are important to relieve fears.

Bereavement Period

- Hospice care does not conclude once the patient dies but usually continues for at least 1 year with bereavement support.
- Even though the family feels they have prepared for the death, facing the future without the person who died is difficult.
- The hospice staff also go through a grieving period for each patient who dies.
- Each hospice provides support to their staff with support meetings and time to vent their feelings and to heal.

Ethical Issues in Hospice Care

- Ethical issues when dealing with hospice patients include withholding or withdrawing nutritional support, the right to refuse treatment, and do not resuscitate (DNR) orders.
- It is hoped that the patient’s wishes are made known in advance, such as by a living will or an advance directive, or that a durable power of attorney has been appointed.

- It is imperative that the nurse be aware of the organization’s ethics policies and procedures so that any questions and concerns may be addressed appropriately and correctly.