The Hospice Concept

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The hospice concept of care for the terminally ill, long practiced in Europe, has recently been gaining acceptance in the United States. Changing attitudes toward health care in general and toward the care of the dying in particular have created a milieu favorable to the development of programs based upon the hospice model. This situation, while a welcome relief to those directly involved in delivering health care services to the dying, has caused some in the field to sound a note of caution. Dunn has noted the danger that some may attempt either partial or substandard application of essential hospice elements. Dobihal has pointed to the possibility of hospice programs becoming "fads," enjoying a transitory popularity soon lost to newer developments.

What Is A Hospice?
The term "hospice" derives from a medieval word for a place of shelter for travelers on difficult journeys. The current use of the term to describe institutions designed to control and relieve the emotional and physical suffering of the terminally ill comes from Britain, where many hospices have been established in the last 10 years, most notably, St. Christopher's Hospice.

With St. Christopher's as their model, many hospice programs have been established in the United States and more are in various stages of planning (Table 1). While there may be differences from one program to another, essential characteristics must be present if a particular program is to legitimately use the term "hospice" (Table 2). A hospice is more than a program of medical health care for the terminally ill; it is a model with specific, recognizable elements. A hospice is an autonomous, centrally administered program of coordinated in- and outpatient services. This physician-directed program of health care delivery employs a multifaceted approach: narcotic and non-narcotic analgesics are used in physical symptom control, and the interdisciplinary hospice team provides psychologic, sociologic and spiritual services as they are needed. The patient and family is the primary unit of care and services are available on a 24-hour, seven-day-a-week basis. Hospice services are also available during the period of bereavement. Patients are usually accepted on the basis of health needs, rather than ability to pay.

Primary Unit of Care

With the great advances made in the diagnosis and treatment of disease, we have,
The hospice approach emphasizes home care, with back-up services by the hospice staff. Here a nurse and a volunteer worker visit a patient (second from right) and her son in their home. (Photo by Linda Bartlett)

unfortunately, too often lost sight of the patient; a patient is not merely a collection of symptoms, but a human being and a member of a family.4

The psychological and social problems that confront both the terminally ill patient and the patient's family are often more distressing than the disease itself; they have extremely urgent and practical concerns. Patients often ask, for example, "How long will it be?" "How hard is it on my family?" "Will the money last?"4

Depression and anxiety plague the relatives of the terminally ill as well as the patient. Unfinished business, a family facing problems of support, long-term plans and dreams destroyed by terminal illness—all these are legitimate sources of concern and emotional stress. Family members also have many questions: "How much does he know?" "What should I tell the children?" "What do I do if there is bleeding in the middle of the night?" "How will I manage alone?" These concerns, as well as physical symptom relief, must also be met by treatment plans.4

Patient/family care generally begins with a visit by a member of the hospice team to the home (Fig. 1). An overview of the family situation is essential: (1) is the patient the sole support or a peripheral family member? (2) what are the cultural and behavioral family patterns? (3) are there any long-term conflicts or tensions in the family situation? It is important for the hospice team to understand the patient/family under both ordinary situations and under stress.4

The family is frequently able to provide valuable information to the professionals on details of care. They may provide explanations of certain expressions unique to the patient, information on the frequency of medication or simply information as to which positions the patient finds more comfortable.3

In the face of the demanding process of caring for a terminally ill person, family members often deny their own needs. This can lead to feelings of neglect and resentment. The hospice team is attentive to these needs as well as those of the patient.
Fig. 2 Family members assume an active role in the care of the patient. Nurses and other staff members guide and assist them. (Photo by Linda Bartlett)

Fig. 3 Central to hospice care is the preservation of the quality of the patient's life and avoidance of isolation from the outside world. (Photo by Linda Bartlett)

Unlike acute illness, where recovery is expected, with terminal illness every family member is affected. Adjustment to life without the patient begins before death and this difficult adjustment often requires professional treatment and guidance.

Hospice caregivers must discover what work a family can do and what it cannot; they must ascertain which family members they can rely on at what time. Active participation by family members is part of the process of separation. It has been observed clinically that those who are actively involved in the process of care while the patient is alive are less prone to guilt and self-criticism after death than those not involved (Fig. 2).

Symptom Control

One of the major goals of a hospice program is to maintain the patient's quality of life. This involves taking those measures necessary — whether pharmacologic, psychologic or spiritual — to keep the patient at his or her optimal level of functioning (Fig. 3).

Physical Symptom Control

Pharmacologic agents are used to cure disease, if possible. If not, their use is palliative. Palliation can be divided into two aspects: treatment to increase the length of life and treatment to improve the quality of life. Physical symptom control in a hospice setting is concerned with the latter.

Inordinate fear of the use of powerful narcotics (e.g., fear of patient addiction) is an impediment to the care of the terminally ill. For example, diabetics do not have to go into a coma before insulin is administered; analogously, patients who are dying should not have to wait until pain appears before medication is administered. Pain medication is titrated for each patient's need and is self-administered when possible.

Chronic pain must be distinguished from acute pain. In cancer patients, the meaning of the pain is different. Anxiety and depression are part of the nature of chronic pain. The patient is worried about
the return of the pain and this anxiety increases the pain. Lack reports5 that at Hospice, Inc. narcotics are used to relieve severe physical pain when non-narcotic medication or other measures (e.g., spinal block or traction) have failed to control the pain. Hospice combines narcotics with phenothiazines, usually Compazine or prochlorperazine. Phenothiazines potentiate the narcotic, allowing a lower dosage of narcotic to be used (Fig. 4). The medication is administered orally. Phenothiazine is also a useful antiemetic and controls the anxiety related to chronic pain. Other anxiolytic drugs used are Valium and Librium (benzodiazepines) either in combination with phenothiazine or, rarely, alone with narcotics.5

The depression associated with chronic pain may be treated with tricyclic antidepressants (e.g., Elavil). Experience in this area is crucial since depression may be an entirely appropriate response on the part of the patient and not require medication at all. However, if depression is definitely a component of the pain, the addition of tricyclic antidepressants can be useful in controlling pain.5

Physician, patient and family fears of addiction must be dealt with before a successful pharmacologic program of pain relief can be instituted.4 Craven and Wald4 note that physical dependence is not a problem in the patient with terminal cancer, psychological addiction is rare, and tolerance does not pose a clinical problem. Twycross6 has noted that much of our information about narcotics comes from animal studies, ex-drug addicts or acute pain (usually given single doses parenterally), and that application of these findings to patients with chronic pain is questionable. Twycross’ studies suggest that common beliefs about long-term use of narcotics may be nothing more than “folklore.”6

Thorough assessment of pain is vital before any drug regimens can be recommended. Such assessment includes:
- Delineation of site(s): Is it localized, diffuse, referred?
- Does certain activity alleviate or exacerbate pain?
- How is the sleep pattern affected?
Is the patient taking other medication? In fact, if sufficient information is elicited from the patient, the need for narcotic analgesics can often be reduced. A patient may complain, for example, of severe headaches. Rather than increasing the dosage of narcotic analgesics, this may be successfully treated with large doses of dexamethasone and by simply elevating the head of the patient’s bed. Adequate information about patient pain can often help eliminate the discomfort through means other than medication.

Perhaps the most innovative aspect of the hospice program is its method of delivering pain medication to patients. Generally, these drugs are self-administered by either the patient or family members. The intention here is to free the patient from dependence upon staff for pain relief and to assume responsibility for the control of his or her pain (Fig. 5). It has been the hospice experience that pain is much easier to prevent than it is to ameliorate after it has made its appearance. Craven and Wald describe a patient on Elavil, Prolixir and a minimum of Levo-Dromoran. Follow-up examination showed the pain well under control and the antidepressant and phenothiazine were discontinued. The pain returned immediately and was uncontrollable despite more frequent administration of Levo-Dromoran. The need for narcotics was reduced when the former regimen was reinstated.

Oral doses of narcotic analgesic drugs are preferred because they provide the patient with greater latitude. If morphine is administered IV, the patient’s options and mobility are severely limited. While some patients may take the medication in

| TABLE 1. SELECTED U.S. HOSPICES |
|---------------------------------|
| Hospice, Inc.                   | St. Luke's Hospice              |
| New Haven, Connecticut          | New York City, New York         |
| Hillhaven Hospice               | Calvary Hospice                 |
| Tucson, Arizona                 | New York City, New York         |
| Hospices, Santa Barbara County, | Rockland County Hospice         |
| Inc., Santa Barbara, California | Rockland County, New Jersey     |
| San Diego Hospice               | Hospice of Orlando, Inc.        |
| San Diego, California           | Orlando, Florida                |

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| TABLE 2.  
| BASIC CHARACTERISTICS OF A HOSPICE PROGRAM |
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| **A. The Hospice Program:**  
Autonomous.  
Centrally administered. 
A program of coordinated out- and inpatient services, primarily concerned with home care, with back-up inpatient services when home care is not feasible. |
| **B. Primary Unit of Care — Patient and Family:**  
Total patient care includes dealing with family and other significant patient relationships. |
| **C. Symptom Control:**  
**Physical:** pain, nausea, vomiting and other symptoms are controlled as effectively as medically possible.  
**Emotional:** behavioral sciences are important in helping patient and family cope with emotional distress accompanying impending death.  
**Spiritual:** attention to human spiritual concerns is equally as important as pain care and is integral to a hospice program. |
| **D. Physician-Directed Interdisciplinary Care:**  
All health care is provided under the direction of a qualified physician.  
The interdisciplinary areas include: social work, physical, occupational and speech therapy, pastoral care, and a wide variety of consultant services (e.g., psychiatric, radiologic, pediatric, oncologic). |
| **E. Trained Volunteers:**  
Volunteers are specially selected and extensively trained; they augment staff services and are not engaged in lieu of staff.  
Volunteers provide vital services other than clinical (e.g., transportation, companionship, recreational and other services). |
| **F. Services Available ON CALL:**  
Hospice services are available on a seven-day week, 24-hour basis.  
Hospice nursing staff bear primary responsibility and call on other program resources as necessary. |
| **G. Staff Support and Communication:**  
Opportunities for staff to discuss their concerns—either one-to-one, or in a group, on a structured or unstructured basis—are imperative.  
Channels for staff discussion, support and mutual evaluation are established. |
| **H. Bereavement Follow-up:**  
Hospice services are extended to the family during the period of bereavement.  
Extent and length of bereavement care is based on factors prior to and following death of patient. |
| **I. Hospice Services Based on Need:**  
Hospice services are based on need rather than ability to pay. |
tablet form, Lack reports that medication can be more finely titrated for each patient in liquid form and is thus preferable. Craven and Wald report using either tablets or the "Brompton mixture." In New Haven, Hospice, Inc. uses a mixture of morphine and a phenothiazine combined in cherry syrup. This "hospice mixture" does not include cocaine, alcohol or chloroform water as does the Brompton mixture. In addition, heroin is not considered necessary for adequate pain control at Hospice, Inc. It is their feeling that morphine is satisfactory for management of pain.  

Other Factors in Symptom Control
Symptom control involves more than the administration of medication. An environment that is peaceful and secure, quality professional care and family and personal involvement all play a role in the relief of pain. In a hospice, behavioral sciences are important in helping patients deal with emotional distress due to impending death. Human spiritual concerns are addressed as well (Fig. 6). All of these elements are crucial to successful management of pain.

In summary, effective pain control necessitates:
- Identification of etiology (all pain may not be caused by cancer).
- Prevention of pain before it appears.
- Administration of medication as simply as possible to allow the patient to self-administer drugs, maintain alertness and live as normally as possible (Fig. 7).

Interdisciplinary Care
To a greater degree than any other group of patients, the terminally ill are better served not by the various medical specialists, but by a medical team with a holistic approach to patient care. The hospice team provides just such an approach, treating the whole person, not merely physical symptoms. The typical hospice team includes the following specialties:
- Social work.
- Occupational, physical and speech therapy.
- Pastoral care (Fig. 8).
- A variety of consultant services (e.g., psychiatric, radiologic, pediatric).
These services are directly supervised by a physician. Patients and their families fre-
HOSPICE, INC.

Hospice, Inc., in New Haven, Connecticut, patterned after similar programs in England, is a specialized program for the management of pain and other symptoms associated with terminal illness. For Hospice, the family is the unit of care and their efforts are mainly centered in the home. The goals of Hospice are:

- To keep the patient at home as long as possible.
- To educate health professionals and lay people.
- To supplement existing services.
- To support the family as the unit of care.
- To help the patient to live as fully as possible.
- To keep costs down.

The Hospice Home Care Team involves physicians, nurses, a social worker, a physical therapist, secretaries, pastoral counselors and volunteers. Staff members make regular visits and are available 24 hours a day, seven days a week. An alert, pain-free existence for patients is the foremost goal of Hospice care.

As of October 1, 1977, the Hospice Home Care Program had served 414 patients and their families. Of these, 322 had died; 56.8 percent of them died at home. Fifty-four percent of Hospice patients are under the age of 65.

Though designed to aid those terminally ill from any cause, to date all Hospice patients have suffered from cancer. This is a direct result of a National Cancer Institute (NCI) contract with Hospice to operate a National Demonstration Center for the care of the terminally ill and their families. In September 1977, the NCI contract—which covered operating costs—expired and Hospice now charges for its services, though many of the costs will be underwritten by third party payers.

State and federal funds, contributions from corporations, foundations and individuals have provided Hospice with funding to break ground for a facility in Branford, Connecticut. There will be 44 inpatient beds, a daycare center and outpatient program and headquarters facilities for staff. The inpatient facility will serve patients throughout Connecticut and provide back-up for the Home Care Program.

Though the Hospice program is non-sectarian, religion is integral, and an interdenominational chapel will provide a center for some of this activity.

Criteria for admission include: (1) the prognosis must be for death in either weeks or months; (2) the referring physician must agree to continue his association with the patient; (3) a spouse, family member or friend must be ready to assume responsibility for primary care; and, (4) the patient must live within a 30-mile radius of Hospice.

Consequently complain that—in the final stages of terminal illness—they feel abandoned by their physicians. At the moment when life-saving measures are no longer available, many physicians, for a number of reasons, feel that their role is at an end and withdraw from the patient. This is not true in the hospice setting. The physician remains actively involved at all times.

While the hospice team is supervised by a physician the major burden falls upon the nursing staff (Fig. 9). Services are provided to patients on a 24 hour, seven-days-a-week basis. It is the responsibility...
of the nursing staff to ascertain patient/family needs and call upon the other members of the team as the situation demands. Interdisciplinary care is a carefully planned effort involving professionals, family, close friends and volunteers (Fig. 10). It is not a fragmented program of care but one that takes into account that no one person can handle all the needs of the dying patient and seeks to meet those needs as completely and humanely as possible.

The Role of Nursing in Hospice Care

As mentioned earlier, the primary burden for patient care in a hospice setting falls upon the nursing staff. The hospice program provides a challenge to the nursing profession in particular and the medical community in general. A sound working philosophy of nursing care is central to any hospice program. This does not mean theoretical analysis but solving the daily problems faced by nurses as they work at the bedside of the dying. It is the practical, mundane concerns that matter: wet bed sheets, physical discomfort, feelings of isolation, insomnia. There is much written and discussed about the emotional and psychological problems of patients and not enough about the practical necessities of ensuring patient comfort.¹,²

Those elements involved in nursing care of the dying are the core of what constitutes nursing itself.¹ Dunn suggests that at any one time a nurse is both a teacher and one being taught, a giver and receiver, a healer and one being healed. These are not abstract concepts but realities that require highly skilled, compassionate and technically proficient nursing personnel.¹ Galton at St. Christopher's in England stresses that nursing staff must learn what the patient needs really are, as opposed to what staff think they are. She reports that quality nursing care entails:

• Imaginative care, unhurried, with attention to detail.
• Learning to perform tasks (e.g., feeding a patient) with patience and devotion, not with a mind on other matters.
• Learning the patient’s mode of communication (e.g., understanding the person who cannot speak or does so with great difficulty).
• Learning to sit quietly with the dying,
to keep them in touch with life as much as possible, with continuous caring until the end.

- Involvement with the family members after the patient's death, to help in the process of grief.  
  Such care requires a higher ratio of staff to patients than does care in a conventional acute care hospital setting. In fact, the emotional strain on all members of the hospice team, not merely nursing staff, has led to the establishment of channels of communication.

Staff Support and Communication

Proper patient care of necessity entails "involvement" on the part of professional staff. In order to provide adequate care, staff must get to know the patient and family, their likes and dislikes, burdens and joys, with the result that human relationships are formed. Opportunities for staff members to discuss their concerns are essential (Fig. 11). This may be structured or unstructured, on a one-to-one basis or within group meetings. However the goal is achieved, such channels for mutual support, evaluation and the expression of normal and appropriate emotional response to human sorrow are integral to a hospice program.  

Bereavement Follow-up

In keeping with the concept of the patient and family as the unit of care, hospice programs provide professional services during the period of mourning for the surviving family members. The grieving are more susceptible to psychological and physical illness and professional medical care for them is entirely logical.  
Some family members, feeling a sense of relief after the death of a relative, rather than a sense of grief, become guilty. Professional care can help resolve this difficulty. Also, the ability to communicate often eases emotional burdens and hospice professionals can help to either initiate or guide this important process. All involved must accept the fact of death and let life go; yet there is a continuity spoken of in all human thought systems that remains and helps the living to go on. These are extremely individual matters and require careful consultation by the hospice team in order to help others find their own answers.
CALVARY HOSPITAL

Calvary Hospital, in The Bronx, New York, delivers a specialized, humanistic program of patient care to those with advanced cancer. It is the only institution in New York City devoted solely to the care of the terminally ill.

Founded in 1899 as the House of Calvary on Perry Street in lower Manhattan, the institution moved in 1915 to its present location. Plans are now underway for a new hospital building that will increase the number of patients served from 111 to 200.

Patients are admitted to Calvary based on diagnosis and immediate need. The decision is made by the physicians’ admission committee. Upon admission, each patient is assigned a personal physician who is responsible for the patient’s care on a continuing basis. The requirements for admission are:

- a medical report indicating tissue proof of diagnosis
- advanced state of the disease
- prior treatment and therapy

The staff at Calvary have found that a close physician/patient relationship is extremely important to those with advanced cancer. A strong personal bond between physician and patient can ease the emotional suffering that accompanies protracted physical pain. The special skills of various disciplines are used to assist and comfort the family facing the loss of a loved one. All procedures are discussed frankly with the patient and family and performed only after informed consent has been given. If desired, therapeutic measures to ameliorate or reverse the cancer process are undertaken; regardless of that outcome, professional skills are concentrated on the relief of physical and emotional suffering.

Calvary is an important predecessor to today’s hospices. Much valuable information on the care of the dying has been gained at Calvary and transmitted to others establishing hospices. For example, Dr. Cicely Saunders, while formulating her plans for St. Christopher’s Hospice, visited Calvary and discussed with the staff the work done there. The major activity at Calvary is, of course, patient care but the institution also has a professional training program in the care of those with advanced cancer. This program is designed to introduce medical students, nurses and other paraprofessionals to a personal, humanistic, holistic approach to the management of the patient with advanced cancer.

Health Care Needs Vs. Ability to Pay

It is the aim of hospice programs to provide medical services on the basis of health needs and not on ability to pay. Currently, these innovative programs are dependent upon grants (whether public or private) and donations. The Federal government is now studying the hospice concept focusing on such issues as cost-effectiveness, licensing, and reimbursement for hospice-style home care. A number of reports indicate that hospice care is much less expensive than acute care hospitals. In one study of 500 patients served by Hospice, Inc., average cost for the last three months was only $750—less than the cost of one week in a typical hospital. It has also been reported that full standing hospices cost approximately 27 percent less than acute care hospitals.9

The problem of reimbursement is not simple by any means. Standards and certification procedures will have to be estab-
The interdisciplinary hospice team meets regularly to discuss program implementation, often on a weekly basis. There are also other established channels for staff to voice concerns and for mutual evaluation. (Photo courtesy of St. Luke's Hospital Center)

**HOSPICE ARCHITECTURE**

Architecture is perhaps one of the less obvious considerations involved in hospice planning. But the design of the building itself may have much to do with the relative success of the facility in achieving its goals. Designing any health care facility is complex, and such highly specialized facilities as centers for the dying present very specific architectural challenges.

Lo-Yi Chan, designer of Hospice, Inc. in New Haven, incorporated a number of features that enhance the efforts of Hospice staff to make the final days and weeks as comfortable as possible for patients and their families. Architect Chan began by creating a building that fit in well with the other buildings on the street. He symbolically eased the anxiety of approaching the facility by designing an extra-long driveway. Inside, too, there are a number of “transition areas” where people can pause, reflect and react as they move from area to area.

“Buildings speak to people on many levels,” says Chan, who was concerned about Hospice being viewed as a ‘death house.’ “My aim in designing the hospice was to create a building that welcomes people.” Hospice has many windows, through which passers-by see growing plants and people moving about in the course of normal activities. In these and other ways, says Chan, the building is saying, “Life goes on here just as it does everywhere else.”

The needs of patients’ families are also taken into account in hospice design, as are those of the staff. Because 24-hour visiting is permitted, much less lobby space is necessary than in an acute care hospital; more of the building’s area can be devoted to rooms that serve the requirements of those involved in the dying process. Such facilities as playgrounds and day care centers for children, chapels and living rooms for families, and private lounges for staff are important physical adjuncts to the goals of hospice care.
lished and the integration of hospice care into any national health insurance program will have to be solved first.

The hospice program is a humane, holistic approach to medical care that has great support among all elements of society. We must protect this innovation from profiteering, commercial exploitation and lowering of standards and supervision. But more, we should do what we can to foster the development of this valuable addition to health care in our country.

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