
Terminal Care—Issues and Alternatives

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AS THE AIM OF CONTEMPORARY MEDICINE moves more clearly to diagnosis and cure, the criterion of rehabilitation potential has been a deciding factor for reimbursable services under Title XVIII of the Social Security Act. However, with the increasing ability of medical technology to prolong life past its natural point, with slight chance of recovery, the prevailing criterion has been questioned. The definition of skilled care in skilled nursing facilities, as published in the September 24, 1975, Federal Register, is that:

The restoration potential of a patient is not the deciding factor in determining whether a service is to be considered skilled or nonskilled. Even where full recovery or medical improvement is not possible, skilled care may be needed to prevent, to the extent possible, deterioration of the condition or to sustain current capabilities. For example, even though no potential for rehabilitation exists, a terminal cancer patient may require skilled services as defined. . .

Such emphasis is characteristic of an increasing interest in death and dying, by the public as well as health professionals, that has triggered greater attention to the care of the terminally ill generally and

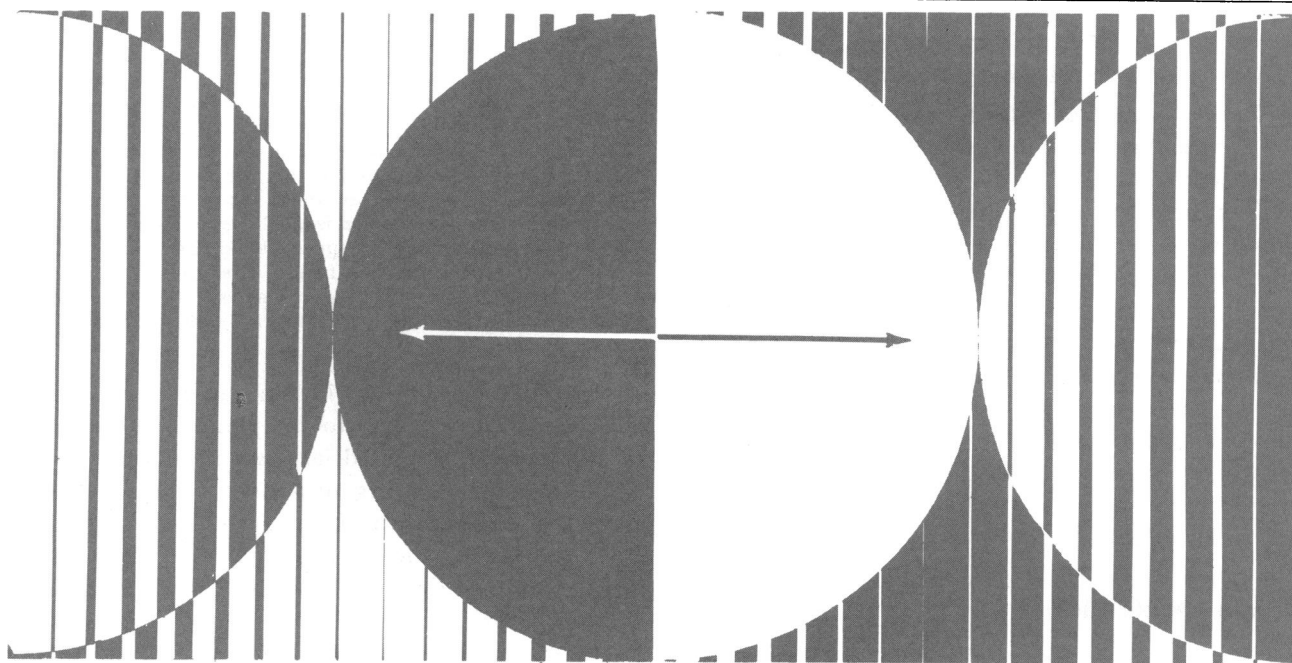
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the needs of individual dying patients and their families. These needs, ranging from relief of physical pain to emotional support, require services that are not readily met in a conventional hospital or skilled nursing facility. Because the aim of treatment is “to preserve life and to relieve distress, to palliate, to maintain comfortable existence as long as possible” (1), many health professionals have proposed removing terminal patients from a traditional institutional setting. Consequently, these professionals have attempted to create programs in home care and in inpatient facilities specifically geared for terminal patients and their families. These innovations will require a change in Federal policy, and, in fact, will demand long-term legislative change, which, in turn, must take into account:

1. The attitude of community leadership, health professionals, and the public to deny the reality of death and needs of the patient and family.
2. Inadequate services to meet the needs of the patient and family.
3. Inadequate financing mechanisms.
4. Inadequate information regarding cost effectiveness of alternatives to traditional institutional care for the terminally ill patient.

Our Changing Society

Basic to our failures in the care of “the terminally ill is the fact that American society in its preoccupation with perpetual youth, beauty, sexuality, and strength has typically disguised, avoided, denied, and embel-



lished death” resulting in alienation of the dying (2a). This isolation has been encouraged by a change in societal institutions, most prevalent of which is the change in family structure, a metamorphosis that followed economic evolution from the extended family to the modern nuclear family. Within the extended family, the processes of the life cycle were an accepted and natural part of daily life, with birth and death on a continuum in nature. Ill persons were cared for in their homes by their families, and the burials of those who died were attended by all members of the family.

With the emergence of industrialization and urbanization, the family ceased to function as the sole support of the individual, resulting in mobility and a schism between occupation and home. The extended family was whittled down as the middle-class young gravitated toward the suburbs and left the old and the poor isolated in urban centers. With the aging thus removed from the nuclear family, the succeeding generations became desensitized to death of the old. In addition, the establishment of hospitals isolated the ill. Therefore, because people rarely saw death, they could avoid it and in doing so, feared it (2a).

Concurrent with technological changes that altered the family structure were those that altered morbidity and mortality rates. From 1900 to the present, the life expectancy at birth has increased substantially, from 47 to 70 years. However, along with changes in overall death rates came changes in causes of death. Infant and maternal mortality rates

have sharply declined, and infectious diseases have been replaced by heart disease and cancer as leading causes (67 percent) of U.S. deaths. Concomitantly, these degenerative diseases are classified as long-term or terminal illness in that the prognosis given indicates a time limit on a person’s survival. Thus, a new problem in the health field is the care of persons with lingering illnesses (3).

Professional Attitudes Toward Death and Dying

The present orientation of the medical profession is not in caring for patients afflicted with degenerative diseases but in curing them. Technological breakthroughs in medicine have perpetuated a phenomenon found among health professionals as well as in the society at large, a phenomenon referred to as “death denying.” Until recently, this attitude was reflected in the training of physicians and nurses. Recurrent in the medical student’s education was the idea that “every death corresponds to a failure, either of the individual physician, or more commonly, of medicine, as a whole” (4a). The student becomes desensitized to death symbols—blood, bone, corpses, and the characteristic stench—and through transference may become desensitized to death itself (4b). In his dedication to the ideals of the scientific community, the physician responds with “vigorous application of laboratory diagnostic tests, technological gadgetry, and heroic therapy in order to prolong life” (4c). Therefore, whereas 50 years ago the physician was considered a member of a consolatory profession, science has now given him omnipotent

powers to keep the vital functions of a body operative by artificial means long after the natural course of disease has vitiated these functions.

Thus, the new orientation of physicians reduces the crux of the problem to the question: When does death occur? Much of the current literature deals with ethical and legal questions surrounding the point of death and delineates problems that occur when the prolongation of life past its natural point preempts death as a natural process. We are now at the point where considerations of quality of life are secondary to concern about the length of life. Quality of life is a subjective assessment, but when applied to the terminal patient as primary to the length of survival, it takes on specific meaning. One can debate whether survival amid tubes and respirators is life at all.

Where People Die

As mentioned previously, the home no longer provides a person with an extensive support system. In light of this, it is not surprising that the death rate in institutions has risen considerably over the past decades. Although national statistical studies pertaining to deaths in institutions as opposed to deaths at home are scarce, some State and local data are available. From 1949 to 1958, a 10 percent national increase occurred in institutional deaths, including those in general hospitals, mental hospitals, and nursing homes. New York City statistics reveal an increase from 53,746 institutional deaths in 1955 to 64,083 in 1967, representing a 7 percent increase, and a 7 percent decrease in deaths at home, from 25,598 in 1955 to 21,222 in 1967 (3). Furthermore, there is evidence that this latter figure has decreased rapidly in more recent years.

Paradoxically, a survey of deaths from cancer between 1969 and 1971 in south-central Connecticut showed that 67 percent of these patients had expressed a desire to die at home as opposed to the 20 percent who did die at home. In addition, this study revealed a significant difference from a socioeconomic point of view. Those in the upper socioeconomic level were more successful in meeting their desires as were many in the low socioeconomic group, although for disparate reasons. The upper income group had the advantage of personal control, private health insurance, and monetary resources to aid in keeping the patient home. However, the low socioeconomic group and lower-middle class were successful because of reimbursement for care services under Medicaid, as well as support supplied by a cohesive

extensive family. The report of this survey, prepared for the National Cancer Institute, identifies the upper-middle class as unique:

In the upper-middle class, the resources of Medicaid are not available and Medicare is only available for patients over 65. It should also be noted that visiting nurses are most effective in a family situation where there are several primary care givers to relieve one another from the emotional and physical burdens of the care. In the upper-middle class family, it is our observation that when the family care giver is a man, he usually keeps on working, ergo the necessity for some form of institutionalization where the upper-middle class has better insurance coverage.

Since 70 percent of institutionalization for the terminally ill pertains to the general hospital, the burden of care is placed largely on the hospital staff (5). However, the organizational structure of the hospital makes care routinized rather than individualized, and is, therefore, frequently inappropriate to the needs of the dying patient. The large teaching hospital's primary functions are diagnosis and treatment of patients with acute illnesses. In contrast, the chronic illness hospital or wing, which houses a large population of dying patients, is generally relegated a lower social status, and thereby has difficulty in attracting funding and quality staff. The hierarchy for patient care in a general hospital is (a) acute illness, (b) chronic illness, and (c) terminal illness (6).

The medical staff adheres to this hierarchy in its orientation toward care. As more demands of physical care of those with acute curable illnesses are met, the psychological and emotional needs of the incurable are more often neglected. Physicians tend to view cure as their triumph and death as their failure; they therefore attend to dying patients as prescribed only by duty. Nurses tend to "pull away" from dying patients and to focus more on the diagnostic and curative aspects that are implicit in their trained professional approach to patients (7). According to Sheldon and associates (8):

... conceptual limitations include an inability to perceive and interact with the psychological and social needs of patients and their families, a lack of effective communication among physicians, nurses, and other ward personnel, and a failure to appreciate the emotional and psychological difficulties that characterize the medical staff's reaction to patient problems.

Patients suffering from cancer are often shuttled from one specialist to another, which results in further fragmentation of care rather than an integration of services encompassing the physical, social, and emotional needs of the patient.

Pain is singularized as physiological pain that can be easily treated with the use of psychopharmacological agents. These agents often replace staff contact,

which, in the case of the dying patient, is already minimized. The psychological experience of the patient and family "is deadened by the use of narcotic and analgesic drugs which reinforce the collusion of avoidance rather than enhance the experience of death" (9). The drugs aid in meeting the goal of patient manageability, essential in a busy hospital.

Terminal patients also die in nursing or convalescent homes, many of which are classified as skilled nursing facilities. These facilities are often not oriented to meet the needs of the dying patient, focusing on physical rehabilitation or restoration rather than on the total needs of the patient. In a 1975 survey of 77 nursing homes (10), a majority indicated that they removed deceased patients as clandestinely as possible so as not to disturb the other residents—a practice that seeks to deny death by making it a covert issue.

Social Death Versus Biological Death

The result of the institutionalization of dying patients is a phenomenon of "social death" prior to biological death, which incorporates "the process of mutual disengagement and rejection by which 'organization man'—more precisely, the human being as a member of society—seems prone to take his leave from the land of the living" (11a). Once the patient has been labeled terminal and the physician has given up hope for recovery, the institution treats the patient as a dying body with little concern for his individuality or humanness. Sudnow (11b), in his study of a county hospital, observed:

When a physician abandons hope for a patient's survival, the nurses establish what they refer to as a "death watch," a fairly severe form of social death in which they keep track of relevant facts concerning the gradual recession of clinical life signs. As death approaches, the patient's status as a body becomes more evident from the manner in which he is discussed, treated, and moved about. Attention shifts from concern about his life, possible discomforts, and the administration of medically prescribed treatments to the mere activity of the events of biological leave-taking.

In a patient who has not yet passed into a death coma, suctioning the nasal passages, propping up pillows, changing bed sheets, and the like occur as part of the normal nursing routine. As blood pressure drops, and signs of imminent death appear, these traditional nursing practices are regarded as less important, the major items of interest become the number of heartbeats and changing condition of the eyes. On many occasions nurses' aides in the county hospital were observed to cease administering oral medications when death was expected within the hour.

When social death precedes biological death in this manner, the needs of the dying patient essentially become secondary to institutional routine. What are these unique needs and how are they met?

Hospice, Inc., New Haven, Conn., in a study of cancer deaths between 1969 and 1971 in the South Central Health Planning Region in Connecticut summarized these needs (5):

(1) the noxious symptoms of the illness, (2) the need to be with family and friends in familiar surroundings, (3) involvement in decision-making, (4) honest and frequent communication, (5) a need to maintain one's identity and role, (6) freedom from heroic measures which become more of an obstacle to the quality of life than even the disease, (7) need for a staff which understands and helps the patient work through anger and depression in coming to terms with dying, and (8) unattended bereavement which results in physical and/or psychological impairment to the survivors.

In a 1975 symposium on the terminally ill, Dr. Balfour Mount, medical director of the Royal Victoria Hospital's terminal patient ward in Montreal, Canada, noted that each need is interconnected and that all needs essentially signify relief from pain. Although all else is secondary to physical pain and must be dealt with before any other consideration, a hospital environment often limits the definition of pain to somatic. An expanded definition would include mental, financial, interpersonal, and spiritual aspects of pain. The dying patient may experience a sense of isolation, especially in a hospital setting, because of a lack of comfort and communication with medical personnel and family. Physicians, in avoiding the reality of death and projecting their fears onto the patient, often choose not to disclose the prognosis of impending death to the patient. Hence, an aura of deceit and convertness hampers the patient's ability to cope with his situation and to take care of unfinished business.

Coping with Dying and Death

The coping process involves several stages, the transition from one to another being facilitated by a neutral uninvolved party, be it physician, nurse, social worker, professional counselor, member of the clergy, or understanding volunteer. The stages, as outlined by Ross (12), are (a) denial, (b) anger, (c) bargaining, and (d) acceptance, each with its unique reactions and communication patterns. The patient experiences these various emotions in regard to his finiteness, successes, failures, family, all tied together into a package of fear, guilt, and an intense desire, on the part of many, to remain independent. The concerns of dying patients, of course, vary with age—the young girl feeling alienated from companions, the mother worried about the burden on her family and the safety of her children, the successful businessman concerned about his finances—all essentially emphasizing the need to retain a unique identity. This

realization of individuality is in conflict with the treatment of only the physical discomfort of the deteriorating body rather than the whole human being with a past and a present.

The mental anguish of a person approaching death is intrinsically bound to interpersonal communication with those who are close to him, usually the family. In actuality, the needs of the family are so closely interwoven with the patient's needs, that to deny the former is to hinder the patient's process of acceptance. Indeed, often the family must experience the same mental stages as the patient's. Communication is enhanced by a realistic, honest expression of feeling through which both the patient and family are relieved of guilt. Often a "game" is played between spouses that consists of hiding knowledge of impending death from each other. Until both parties can communicate and share this knowledge, progress toward mutual acceptance of the inevitable is halted. Again, each patient and family unit's problems and the manner in which they are most appropriately handled are unique.

Financial considerations are an undeniable aspect of the problems of coping with terminal illness. According to a Department of Health, Education, and Welfare Report of the Task Force on Medicaid and Related Programs (cited by Pollack 13), "the catastrophically ill are at almost any income level where insurance benefits (including the most liberal major medical coverage) do not cover the cost of sustaining expensive, long-term illnesses." Generally, those under 65 years of age are not eligible for Medicare and those above a certain income level (specified by each State) are not covered by Medicaid. A study by Cancer Care, Inc., in 1973 (14), revealed that the median cost incurred by the families of cancer patients was \$19,055, which is 2½ times more than the median family income of \$8,000. Such universal inability to meet the high cost of hospitalization, surgery, and other treatment strikes hard at the nerve of the patient's guilt, as he may feel personally responsible for the foregone education of a child or the general depletion of the family funds for the future. Financial difficulties may trigger maladjustments as family members may be forced to adopt new roles; for example, housewife turned sole supporter.

Of course, the spiritual needs of a patient are an individual matter. Each person copes with religion or the absence of religion in his own way. Although some attempt to deal with death as the cessation of existence of the mind and body, many patients need to view their death in a religious context, either in relation to a deity or to nature, or both. There are

as many perceptions of death as there are people, including concepts such as an indestructible soul, continuation with nature, reunion with Christ, or continuity through survivors. Each patient should be encouraged to express his feelings about death.

The ultimate culmination of a dying person's needs is dignity of personhood in living and in death. It may be argued as to the definition of "death with dignity," some attesting that this implies accepting death, others claiming that this infers dying in the fashion in which one lived; for example, a hostile person would die with the grudge he carried with him through life. Nevertheless, the crux of dying with dignity is in retaining one's individuality, be that in acceptance or denial, anger or serenity, without the humiliation of unnecessary life-prolonging machines.

Although the concerns of the patient cease with the end of his life, the problems of the family linger; in fact, they often intensify with the patient's death. The length and pattern of bereavement is contingent upon the relationship of the survivor to the deceased and the degree to which communication channels were open during the dying process of the patient, relating to identification with the patient, working through ambivalent feelings, and the satisfaction of mutual dependency needs (15). Hospital environments seldom are conducive to laying the groundwork for a normal bereavement period as relatives are rushed in and out at prescribed visiting hours, children are not allowed to visit patients, and there are incidents of the family being pushed into the hallways while the patient is pronounced dead by a hurried physician who is not capable of dealing with the emotional reaction of the family.

The Hospice Concept

In attempts to deal with all these very special needs of the dying patient and his family, various plans in the United States and Canada have adopted the paradigm of caring for the total patient and family needs with the ideals set forth in the hospice concept. This concept is used in two British facilities which serve as prototypes. Saunders (16), medical director of the largest of these models, St. Christophers' Hospice in London, speaks of the goals of this concept as individualization of death and relief of distress:

The name hospice, "a resting place for travellers or pilgrims," was chosen because this will be something between a hospital and a home, with the skills of the one and the hospitality, warmth, and the time available of the other and beds without invisible parking meters beside them. We aim, above all, to recognise the interest and importance of the individual who

must be helped to *live* until he dies and who, as he does so in his own way, will find his "own" death with quietness and acceptance. A staff who recognise this as their criterion of success will not find this work negative or discouraging and will know that it is important, both in its own right and also in all the implications it holds for the rest of medicine and, indeed, the rest of life.

St. Christopher's Hospice is a 54-bed inpatient facility for people who are in the advanced stages of neurological and malignant diseases. The foremost concern is the relief of the symptoms that often become so closely interwoven with mental anguish. Common problems in addition to pain are nausea and vomiting, constipation, diarrhea, anorexia, and anticholinergic effects. It is essential that the patient be as symptom free as possible, so that the dying does not derive from the symptoms rather than the disease. Tension and anxiety can result from the common practice of withholding medication until the pain has become incapacitating. Furthermore, this may cause the patient to become dependent, not only on the drug but on the person who administers it. St. Christopher's Hospice makes a practice of giving a fixed dosage continually in anticipation of the pain so that the patient never knows the severe potential of the pain. A common pain killer used for this purpose is Bromtom's mixture, a concoction of heroin, cocaine, alcohol, and fruit syrup—understandably, the possibility of addiction is not of concern. In addition, steroids are used to enhance the sense of well-being, to improve the appetite, to relieve pain and lower the narcotic dose, to reduce inflammation, and to alleviate weakness. In short, great care is given to the relief of pain and, in turn, to relieve mental anguish and to facilitate awareness of the experience of living until death.

The importance of living until death as a positive fulfillment necessitates an interdisciplinary staff. Each aspect of care is essential to meet the goal of total patient and family unit, including physical, mental, interpersonal, and spiritual elements. As the primary evaluator and prescriber of a medication regimen, the physician is an essential member of the hospice team. His concern for the patient's mental and physical comfort moves him to open channels of communication. As Cotter observes (17):

In ways unique to the relationship with each individual patient, caring enables the doctor to discern the patient's desire to discuss the future course of his illness, the nearness of his death, and the circumstances which may surround it, as well as the ways in which his family may best be supported in bearing this knowledge.

This sharing allows both the patient and family to discuss matters openly and permits them to "say

goodbye," which studies have revealed as important. The physician is essentially in a omnipotent position to help this exchange or to "inflict wounds by his own thoughtlessness or need to hurry away from something that is very hard to witness" (18).

In the hospice, the nursing staff must be sensitive to the elements of human dignity. They must be aware of individual differences and responses in personal care because many patients have become quite helpless, and the nurses must convey feelings of compassion and understanding for the person's integrity and retention of uniqueness. The nurses must relay any changes in the patient's condition to the physician, so that appropriate adjustments may be made in medication as well as to the patient's daily needs for food and fluid intake, oral hygiene, and body positioning. Cotter points this out (17):

Taking time to explain procedures, to honor preferences, to respect privacy and modesty, to consult with the patient concerning his feelings and his needs, to involve him in social and recreational activities and in small celebrations reflect the nurse's recognition of the patient's personal worth and convey to him the certainty that he still matters, that he has not been "written off" as finished.

The emphasis on religion in this therapeutic community takes on a new meaning of the spiritual. At St. Christopher's, a church-based institution, there is an involvement of clergy and other church-based personnel whose vocation is founded in such work. However, there is an active application of McMurray's definition of religion that "it is the field of personal relationships between people prepared to give themselves to each other in the context of a common life" (19a). The religious commitment of St. Christopher's is thus manifested in its very existence as a community of vulnerable, caring, and involved people, including professionals, volunteers, patients, families, and visitors.

Although substantial attention is given to inpatient care within the physical structure of St. Christopher's, where 400 patients die each year, 10 to 15 percent of the patients are discharged home for a period of time before death. The staff realizes the value of home care by allowing the patient to feel a part of his family and to return to a relative degree of normalcy, however limited and temporary.

In essence, St. Christopher's Hospice has successfully combined the art of medicine with its value and judgment, with the science of medicine to assuage the pains of patients as they approach death, and with help for their families. The prevailing ideology is succinctly summed up in Saunders' assessment (19b): "There is a stage when the treatment of a

hemorrhage is not another transfusion; but adequate sedation, or someone who will not go away but will stay and hold a hand.”

An American Model

In an attempt to fill the existing gap in the health care system regarding services for the terminally ill, various facilities and organizations have incorporated the ideals of St. Christopher's Hospice. The most successful U.S. model to date is Hospice, Inc., of New Haven, Conn. Under a National Cancer Institute grant, a 44-bed inpatient facility for cancer patients is being planned. Using St. Christopher's Hospice as a model, Hospice, Inc., services are meant to (5):

(1) provide medical care for the continuing control of symptoms such as pain, nausea, anorexia, etc.; (2) concentrate on bedside nursing to provide comfort, close attention to easing physical distress, slow lengthy encounters that allow for the patient's care, interpersonal interactions, attention to feeding, emotional support, etc.; (3) focus on the family unit and allow the patient and family to use the assets of their life-style to cope with the situation; (4) include the patient and family by being very careful to develop good open communications; (5) involve the community by including volunteers, many of whom are widows or widowers, in varied activities from assisting with patient care to gardening, assisting in the day-care center, helping in the business office; (6) provide spiritual care through ecumenical services, discussion groups, and through an atmosphere of love and concern; (7) include an outpatient and inpatient program to provide a comprehensive program to meet different patient/family needs; (8) have a carefully constructed facility which fosters a spirit of friendliness, encourages individuals to participate in life, and is more homelike than hospitals; and (9) have built-in supports for staff and volunteers so that they can carry on a demanding work.

Since March 1974, Hospice has serviced 85 families through its home care program, guided by the philosophy that, it is hoped, will continue through completion of the inpatient facility—that the patient should be maintained in the home as long as possible before being institutionalized. The program is under the medical direction of Dr. Sylvia Lack, who heads a staff consisting of two part-time physicians, six registered nurses, two licensed practical nurses, a social worker, a director of volunteers, and an admissions registrar. Consultant staff includes a clinical pharmacologist, a psychiatrist, a radiologist, and a physical therapist. In addition, there are 50 volunteers who had been carefully screened and given extensive orientation before they were assigned to specific patients. The home care program is coordinated with hospitals in the vicinity and includes medical and nursing consultation and family counseling and pain consultation and services on a 24-hour-a-day basis. All staff members are available on call, through an answer-

ing and paging service—an essential element, not only for complete service but for the confidence of the patient and family unit of care. Eligibility for participation requires residence within a specific geographic area and is contingent upon a referral from a primary care physician who is involved throughout the duration of the patient's illness.

The success of Hospice, Inc., has established the program as a national demonstration center and has encouraged other medical and nursing personnel to investigate possibilities for establishment of similar programs in their respective geographic locations. One such program operates under the title Hospice of Santa Barbara, Inc., a nonprofit voluntary agency incorporated in December 1974. Since September 1975, it has been operating as an information and referral service for those terminal patients and their families who suffer from uncontrolled pain of a physical, psychological, social, or spiritual nature. No special plans have been made as yet regarding an inpatient facility, because the present focus is on the home care program, which started on a pilot basis on December 1, 1975. The program was certified as a home health agency with contracts with two visiting nurse associations for the provision of skilled nursing care. The personnel of Hospice of Santa Barbara include a medical social worker, a part-time physician, a part-time pharmacist, a medical records librarian, and an executive director.

Other Care Programs

This emphasis on home care must not be underplayed. Studies have revealed that people prefer to die at home or, at least, remain at home for as long as possible, for they often feel lonely and isolated within a sterile institutional setting. Within this framework, an increasing number of institutions, which do not care for the terminal patient within the facility for monetary or other reasons, nevertheless do provide home care services. In addition to being psychologically preferred by many patients, it appears from informal statements that the cost factor for home care is well below that of hospitalization. For example, Dr. Balfour Mount, at the symposium mentioned earlier, claimed that his hospital's home care program saves the equivalent of \$100,000 per year as compared to the cost of hospitalization. Jack Lally of the Cardinal Ritter Institute of St. Louis, Mo., a home health agency, cited the following comparative figures based on the actual cost of home care for 140 terminally ill patients for about 4 months in contrast to what the

cost would have been for varying patterns of care for that same period in 1972:

<i>Source of care</i>	<i>Cost</i>
Home	\$ 94,000
Hospital	1,768,000
Nursing home	350,000
Home and last 2 weeks in hospital	162,000

Although it is apparent that home care is both economically and psychologically feasible, it is not adequate by itself—rather, it is most effective when used in conjunction with some type of facility, be it hospital, nursing home, or hospice. There often comes a point when a family is no longer able to keep the patient at home for medical or emotional reasons. In fact, there is often an interplay throughout the illness between institutional and home care. This shuffle between hospital, home, and nursing home poses a problem in reimbursement policies under Medicare in that admission to a skilled nursing facility after a prolonged stay at home must be preceded by a 3-day hospital stay before reimbursement can be made.

As the movement for hospices has grown, many institutions have incorporated the ideals set forth by St. Christopher's Hospice within a conventional hospital setting, as a separate ward for the terminally ill. Lamerton cites Saunders' support for a separate unit of care (20):

A unit for patients with advanced or terminal cancer does not have the challenge of diagnosis nor difficult decisions to make concerning radical treatment. It does not have the interest and encouragement of cure and only rarely of remission, but it is easier for its workers to look at their patients as people, to spend time with their relatives and concentrate on the relief of distress whenever it appears. Above all, it should be easier for them to give a patient the kind of unhurried attention he needs so greatly.

This is the philosophy behind the Life Acceptance Program in the Pinecrest Hospital of Santa Barbara, Calif. Within this unit, which has a fairly rapid turnover, there are from 6 to 12 patients at any one time. Two problems exist: (a) because of staffing needs and other undefined logistical reasons, the unit is required to include stroke rehabilitation; this presents a conflict since the rehabilitative needs of the stroke patient are quite divergent from the needs of terminal patients who have no rehabilitative potential and (b) frequently, physicians do not assess patients as terminally ill until they are semicomatose, thus giving the staff a brief and inadequate 48 to 72 hours to get to know a patient and his family. Because such care for patient and family is not begun until the patient is transferred to this special ward, fragmented care results.

A strong argument is made by Lamerton against the isolation of the dying in a general hospital (20):

I do not see a special terminal ward within a general hospital as a good solution, either. Those nurses who did not want to do this kind of work would dread being posted to the ward and would not be the right people to work in it. Matron (or do I mean the chief, principal senior, or nursing officer?) would be overheard to say, "I can't help it, we have three nurses off sick in the acute surgical ward; they'll just have to be brought from the Dead End." Consequently, the terminal unit would be permanently understaffed.

Another case is made against the segregation of the terminally ill in the philosophy and practice of Veterans Administration programs for these patients. Their policy is that such isolation is highly detrimental since the patient is thus labeled as dying or "hopeless." Others have verbalized this objection, which appears to be valid when viewed within the context of a society that has not, on the whole, considered death a natural process. With this in mind, indeed such labeling can be deleterious.

Thus, the third alternative to employing the hospice concept is the hospital that does not segregate its terminally ill, but caters to their special needs. One such plan is used at the Harrisburg (Pa.) Hospital, a 450-bed general hospital, where the success is attributed to one nurse, Joy Ufema. She, dubbed the "death and dying specialist," claims that the hospice concept is more dependent on an administrative commitment than on an edifice. Working as the patient's advocate, she has developed the skill of listening, allowing the patient to make his own decisions by asking: What do you need? Whom do you need? When do you need it? She then proceeds to satisfy these needs, with the help of a very cooperative social service department and the patient's family.

The Harrisburg model is used by hospitals that have some plans for a terminal unit, but for financial and logistical reasons, the plans remain long range. There are indications that some members of hospital staffs, often a member of the clergy, are attempting to attend to dying patients in a unique way. Rev. Leroy Joesten, pastoral care director of Lutheran General Hospital, Park Ridge, Ill., in a personal communication, described the staff's orientation:

It is important to say that our hospital's approach to care of the dying is to deal with it in the total context of care and treatment of a disease. Hence, each of our medical and surgical units functions from a multidisciplinary model directed at "total patient care." This total care attempts to address terminal care needs for patients, family, and staff as well as curative and palliative care needs.

The key to this type of care is a commitment by the entire staff—administration, medical, nursing,

and social service. However, the feasibility within the framework of a general hospital is dubious because, as previously discussed, hospitals are routinized for the purpose of curing the acutely ill. Catering to dying patients' needs is often at the risk of disrupting patterns that, perhaps, were created for efficient and effective treatment of those with rehabilitative potential. The individual needs of terminal patients seemed to be best tended outside such an environment.

Cost Factor

The case for the viability of a hospice as a freestanding facility can be argued on two fronts: (a) care effectiveness and (b) cost effectiveness. Thus far, most of the literature has dealt with the effective care factor. It has been shown that the present orientation of medical personnel, hospitals, and nursing homes, as it exists today, is incompatible with hospice ideals. The cost factor has only been estimated without the aid of a formalized study. Lack (21) projects a cost of \$105 a day in New Haven for a hospice room in 1977-78, the planned completion date for the inpatient facility. This figure should be compared with an estimated \$190 a day in a general hospital in that vicinity, at that projected time. The cost differential is attributed to a hospital's overhead costs due to "the operating rooms, the specialized care areas, the machines for extending life beyond its natural term" (21). Although services that are integral to patient assessment and treatment will be included, such as a pharmacy with a full-time pharmacist to provide the pain-control medication needs, diagnostic radiology, oxygen, suction systems available at every bed, and a small laboratory to conduct the most frequently administered testing procedures, Hospice, Inc., of New Haven will rely on neighboring hospitals for services such as chemotherapy, palliative radiation therapy, and surgical units, if necessary.

The cost factor also includes the price of erecting special structures. Hospice's 1975 annual report quotes \$1,325,000 for planning and building the facility. The consideration to be made is whether the amount saved over general hospitalization costs merits the high cost of building new facilities when there is a plethora of beds in existing community hospitals. In a 1975 lecture in Branford, Conn., Mount cited a possible impracticality in reference to St. Christopher's Hospice, which serves 54 patients within a 6-mile radius: "This does not encompass even half the target population and leaves 70 percent of the patients in need dying in institutions." Thus,

the incurred cost of building hospices may benefit only a minority of those in need, while simultaneously diverting attention from demands that need to be met within hospitals.

Summary and Conclusion

The most desired goal for patients and concerned health professionals is home care for the terminally ill. The familiar surroundings and faces help to relieve the psychological suffering encountered in the dying process and allow freer communication channels between patient and family. However, it is apparent that during some point in the last weeks of life the patient may require closer medical supervision for pain relief, or the family may not be able to continue care once the patient has reached a certain phase, thereby warranting some type of institutionalization. The present choices are, basically, acute-care hospital or nursing home, but, as presently structured, these settings are too often inappropriate to satisfying needs of the terminal patient and family unit. An innovative, yet long-awaited alternative is the use of the hospice concept, which aims at anticipatory pain relief, as well as the psychological and comforting aspects of terminal care.

No extensive cost effectiveness study has yet been undertaken comparing hospital and hospice costs, taking into account the cost of planning and construction. In addition to assessing the feasibility of putting financial resources into these facilities, such a study would have implications for possible legislative changes regarding the 3-day hospitalization requirement for Medicare reimbursement. If indeed the cost of hospitalizing for 3 days before hospice care is greater than direct admittance to the hospice, it should not be classified as a posthospital extended-care benefit for Medicare purposes, but rather as a separate category of care facility that would need to be defined.

Because the development of hospices is a long-range goal and hospices may be able to serve only a portion of the target population, short-term goals should focus on ameliorating conditions for the terminally ill within existing hospitals and long-term care facilities. To do this, an extensive educational program should be organized in medical schools and in institutions, not only to teach methods of pain control and how to deal with dying patients, but also to enhance the concept of death as a natural process. Instruction dealing with psychological management should be an integral part of the training of physicians and nurses, as should continu-

ing education of the same content for hospital staff.

As stated by Schoenberg and Carr (2b):

Many university and teaching hospitals hold "death conferences" when a patient dies in order to determine if any additional efforts could have been expended in order to prolong the life of the individual patient. An appropriate parallel would be a "life conference" preceding death to determine what steps should be taken to assist the patient, family, and hospital personnel in managing the painful feeling of grief, guilt, depression, anxiety, and anger.

Of course, some professionals perhaps have a greater affinity than others for working with dying patients and their families. These people should be engaged as specialists in terminal care and be responsible for integrating efforts for a system of continuity of care. The result, it is hoped, would be an increased ability on the part of health professionals to recognize the unique and individual needs of these patients within an acute-care hospital. Although all hospital staff should be sensitized to problems in terminal care, the most effective management should probably take place in a separate ward where all staff would be specialists. Such a ward should be an appendage to the hospital in structure only and operate under a different routine and set of regulations that are more applicable to terminal care than to acute care. In short, the goal is to use existing facilities and expedite proper and appropriate care as a hospice within a hospital until such time that hospices are established in geographic areas where they are able to serve a large enough segment of the target population to be cost effective.

Because Medicare primarily covers people over age 65, a definite gap exists between reimbursement policies and the reality of occurrence of terminal illness, inclusive of all degenerative diseases. A large number of these diseases occur in people under 65, including children. The costs of care are so exorbitant that these illnesses are correctly categorized as "catastrophic," in regard to the devastating effect on patient and family, emotionally and financially. Legislative policy should parallel the need of a large segment of the population who are unable to meet the costs incurred by a long illness that ends in death. Just as patients with end-stage renal disease are eligible for reimbursement under Medicare, so should those afflicted with other catastrophic illnesses. The combined efforts of legislative change, educational programs, and realistic institutional changes emanating from the cultivation of medicine's art should aim at overcoming the defense mechanisms in the presence of death—denial, withdrawal, and avoidance—which manifest themselves in present institutional and professional practices.

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