The Integration And Implementation Of The Hospice Care Concept In A Community Setting

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THE INTEGRATION AND IMPLEMENTATION OF THE HOSPICE CARE CONCEPT IN A COMMUNITY SETTING

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Dedicated to my father,

whose life taught me compassion for those in need, and whose death compelled me to seek answers.
TEACH ME TO DIE

Sunlight filters through my window
Falling from the sky,
Time slips like a silent stranger
Softly passing by,
Life goes on in busy circles
Leaving me behind,
Memories, like portraits,
Fill the attic of my mind.

Teach me to die,
Hold on to my hand.
I have so many questions,
Things I don't understand.
Teach me to die,
Give all you can give.
If you'll teach me of dying,
I will teach you to live.

I know that it isn't easy,
Seeing me this way,
And it hurts to watch me
Lying here day after day.
Trade your fear of parting
For the faith that knows no pain,
Don't be afraid to say "Goodbye"
I know we'll meet again.

-- Deanna Edwards
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I've found a rainbow in each of you. Thank you for shining on my life!
SPECIFIC AIM

THE INTEGRATION AND IMPLEMENTATION OF THE HOSPICE CARE CONCEPT IN A COMMUNITY SETTING

Hospice is a medieval term. It denotes a place designed for the provision of comfort and hospitality to travelers along the road. In the case of the hospice movement, the road is the course of terminal illness and the travelers are the patients and the families of those patients. Hospice is a health-care program that offers the kind of continuing care that enables the patient and family to live out their lives together as fully and comfortably as possible (Lack & Buckingham, 1978).

Hospice, an alternative method of health care for the dying, is in the beginning stages of development across the nation. Involved in that development are the general public, policy-makers, and health-care professionals.

The medical system is a dynamic social system influencing us all. Our birth, sickness, health, and death are controlled by the social assessment of medical technology. Further, this social organization is professionally controlled by the physician. Any change or interaction in this system is considered dysfunctional if not of iatrogenic origin, a term denoting physician direction.

Hospice seeks to transform this predicted social system by incorporating lay persons and human care into this network of professional care and also by returning some of the control to the consumer, the dying patient.

Implementation of a hospice program of care in a given community must be based on the basic ideals of the concept and on the community's needs and resources.
Inherent in the successful integration of this care process into a community setting is the attitudes of persons involved in the medical social system. These attitudes may well influence whether the hospice movement will provide a "separatist" or "integrationist" model in the health care system of a community.

Posited in this thesis is the hope that the implementation and integration of the hospice care concept will indeed influence mainstream medicine to achieve the best care, both medically and humanely, for the dying.
CHAPTER I

INTRODUCTION

An inescapable fact of existence is the eventuality of death. Though we can know nothing about our own death phenomenologically, the anticipation of death permeates many aspects of individual concern (Thauberger & Thauberger, 1974). Francis Bacon said, "Men fear death as children fear to go in the dark; and as that natural fear in children is increased with tales, so is the other" (Markson, 1971).

Death is a social phenomenon, as is the process of dying. Despite the fact that each individual is born alone and ultimately dies alone, very few individuals die in isolation without the proximity of others. Even if a person were to die in isolation, the dimensions of death and dying may still be considered a social phenomenon in as much as death befalls individuals who are usually members of continuing interaction systems. Thus, a change in one variable of the system has subsequent consequences for other constituents of the system and for the system as a whole (Thauberger & Thauberger, 1974). The patterns of interaction surrounding the process of dying usually have many dimensions and in many instances include economic, religious, medical and familial aspects. Recognition of these interrelationships revolving around the dying person validates dying as a social phenomenon.

In discussing the larger societal dynamics of the death issue, Parsons (1951) has indicated the absence of any society which is without both cultural and social structuring of ideas about death, attitudes toward it, or behavior
in the presence of imminent death or its recent occurrence. Further, Vernon has noted that experiences which the living have had with the deceased are not discontinued abruptly but are symbolically continued and terminated in a non-hasty manner (Thauberger & Thauberger, 1974). Thus, the importance of sharing memories of the loved one is ingrained in the grieving pattern of Western culture.

Western attitudes toward death have undergone a process of change over the centuries. Ivan Illich interprets this change as the process of becoming 'medicalized' in his book, Medical Nemesis (1975). In support of his interpretation, Illich depends on the work of the social historian, Phillipe Aries, who sees the development of Western attitudes to death in terms of four stages of historical development. The first stage is that of "tamed death" and is found in traditional peasant societies and in the early Middle Ages up to about the tenth century (Boyd, 1977). This kind of death takes place at home, in bed, surrounded by friends, family, even children. The dying person prepares himself for it through ancient customs and ritual gestures. Death is experienced as part of the collective destiny, something that is essentially commonplace and taken calmly.

According to Aries, things began to change in the later Middle Ages as greater emphasis was placed on the significance of the moment of death and the art of dying. Death has now developed into "one's own death," the second stage (Boyd, 1977). The dying person in this historical stage still conducts the old collective rites, but with a new consciousness of his significance as an individual.

Around the sixteenth century another shift in the development of Western death attitudes takes place. Death begins to be experienced not as part of the natural order of things, but as a violent irrational rupture
of daily life. The family of the dying person is now expected to take more responsibility in the ritual. The survivors are now expected not just to show grief, but to feel it. Customs of prescribed mourning were developed during this period (Boyd, 1977).

From the seventeenth century onwards, therefore, according to Aries, individuals in the West begin to think of death as something that happens to another, particularly a significant other. Thus, the third stage of development — "thy death" (Boyd, 1977). This attitude characterized by the sense of unnaturalness and by the need to respond to death with feeling and ritual becomes emotionally exhausting for the family who assumes the new responsibility for the conduct of death. Thus, by attempting to spare themselves and the dying person undue stress, the family begins to seek ways of avoiding strong emotion in the presence of death.

The fourth stage of development according to Aries, is the notion of "forbidden death", the concealment of the reality of death (Boyd, 1977). In the twentieth century, this end is achieved when the family hands over responsibility to the hospital and death occurs under sedation, surrounded by professional strangers, and perhaps without the individual concerned ever realizing what is happening. An "acceptable style of living while dying" has been achieved.

This apparent concealment or denial of the reality of death is evident in a review of the literature of the past few decades. In 1965, Kalish conducted a literature search and found less than 400 works written in a twenty-year period (Thauberger & Thauberger, 1974). Death in the twentieth century became a taboo topic. Galser and Strauss note the apparent unwillingness of Americans to talk openly about the process of dying while Fulton and Geis (1978) point out that death in secular societies is not considered
a polite topic of conversation except among the elderly. The relegating to others of various tasks like funerals and burials and the quickly planned disappearance of the dead are indications of the avoidance tendencies of Western culture. These are in contrast to previous centuries when people virtually surrounded the dying and the deathbed scene was an important sociological phenomenon.

Health-care professionals have become increasingly involved in the social interactions around the dying process. The physician's role has evolved from that of a guest in the background of the deathbed scene to the leading actor in determining the diagnosis of death and the frequency and type of social interactions of family, relatives and friends of the dying person.

The family in modern times has stepped back and allowed the health-care professionals to fight a last ditch, and often successful, battle against death in the hospital. The hospital is the doctor's territory and the patient is now his ward; his mission is to save lives, not to stage deathbed scenes, no matter how memorable these may be.

An element of denial emanates from this interaction system of professional care. Death is an affront to the modern physician and his associates. Physicians often subscribe to the aphorism "where there is life, there is hope". They have been trained to keep patients alive and to consider anything else would be an admission of failure. Modern technology equips them to evade this ancient enemy as never before.

Kastenbaum and Aisenberg contrast the modern avoidance of death to previous centuries when people were in frequent contact with the dying (Thauberger & Thauberger, 1974). They assert that the frequency of death occurrences in the environment is in direct variation to the acceptance of
death. If their reasoning is accurate, then it could be predicted that those individuals, in present times, who have the most contact with death and the dying would be least avoiding of this phenomenon. In this respect, the medical profession should be very accepting of death. This, however, does not appear to be the case. Elisabeth Kubler-Ross, a noted psychiatrist, pointed out that approximately 9 out of 10 medical doctors, when approached for permission to talk with one of their patients, reacted with discomfort, annoyance, or overt or covert hostility (Kubler-Ross, 1969). Often physicians visit with decreasing frequency the longer a terminal patient is hospitalized, and nursing care decreases as a patient's death becomes imminent. As death approaches, the interaction between patient and staff becomes strained and patient care is affected (Mount, 1976).

The major function of the hospital is thought to be total patient care. What is not clear is how the patients of this social system, including families, medical staff and, of course, the patients themselves are interrelated. Some of the component interactions with respect to the quality of patient care must be delineated. Of particular importance in this analysis of the meaning of death is the consideration of the values the dying individual places upon himself as well as the value other members of the system place upon the dying individual.

Diggory and Rothman found empirical support for their hypothesis that to the extent that the goals a person values highly depend on his social status, his fear of various consequences of his own death should vary with his status and roles, whether defined by age, sex, social class, religion or marital condition (Thauberger & Thauberger, 1974).

Implicit in this matter is the assumption that the biographical characteristics of an individual are associated with the individual's own
values and subsequent personal interactions with others. This is further supported by Kalish's research conclusion that dying people were more avoided as friends, neighbors or even visitors to the country than were Negroes, Mexican-Americans, Jews or other discriminated-against ethnic minority groups (Thauberger & Thauberger, 1974).

A study by Glasser and Strauss further asserts that the social value, the total of the valued social characteristics which the dying patient embodies, indicates the social loss to family, occupation, and society on his death. The social value a nurse or doctor places on a patient will influence the patient's care as well as the loss experienced at the time of the patient's death. In regard to this, low social loss patients (e.g., alcoholics) tend to receive minimal or even less than minimal care, while those patients with high social value (e.g., college professors) tend to receive extra care (Thauberger & Thauberger, 1974). This social loss factor may also be a variable in the impact of the patient's death on the medical staff. Awareness of various social values could serve to increase the quality of patient care given to the dying.

Dying persons of today no longer fill a well-defined social role. The distinction between the roles of sick and dying has been lost in our medicalized society, and as a result, the care of the dying has suffered. Clarification of these roles is necessary.

The social role accompanying illness was first described by Talcott Parsons (1951). As with other roles it is a constellation of expectations involving rights and duties. In the sick role there are two rights and two duties. Within this role a patient is exempt from the responsibilities of his usual social roles without fear of censure or loss. He is not responsible for becoming ill and, consequently, members of society, particularly
the family and the physician, become obligated to him. Like other social roles, the sick role determines how a person perceives his situation and himself. Both the sick person and the well family and physicians perceive a set of reciprocal obligations (Noyes, 1977). Because society regards illness as an undesirable state, the duties of the sick person are to wish to get well and to seek competent help to do so.

The social role of the fatally ill person is like that of the sick person, time limited. However, while one terminates in the restoration of health, the other ends in death. Both are conferred by medical authority by a diagnosis, which for the dying person carries an unfavorable prognosis. The physician is obligated to the patient to estimate the expected length of life in terms that reflect the limitations of his knowledge. Doctors cannot make the crucial decision that a person ought now to enter the dying role that is up to the patient and the family. Many doctors do not consider the dying role as independent but instead continue their supervision of the patient as if he were still in the sick role struggling for cure.

The miseries and indignities which are a necessary accompaniment of medical treatment are submitted to only because one's life may be saved and recovery is possible. Once the person chooses to enter the dying role, these measures no longer need be expected of the physician to perform or the patient to endure.

As a person enters the dying role after having spent an inestimable amount of time in the sick role, it is important for him to desire to remain alive. By this desire he assures society that he is without responsibility for his approaching death. The obligation appears to continue in some degree as long as the family and friends maintain meaningful attachments to the dying person.
A sick person temporarily vacates his social roles. The dying person is obligated to transfer his roles to others on a permanent basis (Noyes, 1977). He is obligated to exercise choices he may have and arrange for an orderly transfer of property and authority. This process of "putting one's house in order" assures a smooth transition after death.

They dying person is also obligated to avail himself of the necessary supports to life and to cooperate in their administration. He is not expected to remain dependent upon the physician who has already, in the process of diagnosing a terminal illness, transferred him to the dying role. Having done so, the physician no longer holds a position of primary importance in the person's care. Some involvement of the physician seems to be expected even though society reserves the physician's role for the supposedly more important restorative function and jealously guards the physician's time and energy.

Other expectations of the dying individual are cooperation in the curtailment of freedom and loss of privileges imposed by caregivers (Noyes, 1977). He is expected to abide by institutional rules and by the medical professionals' assessment of his capabilities. Independence is also encouraged within the limits of an individual's declining resources.

The dying person has a right to exemptions from social role responsibilities and commitments. As he undergoes physiologic decline, he is free to withdraw from active engagement in the social system of which he has been a part. According to Dumming and Henry's theory of disengagement, as an individual dies his attachment to and interest in the world around him diminishes as do his needs and abilities to respond to those attachments (Noyes, 1977).

Another right of the individual who is dying is to be taken care of.
As in the sick role, reciprocal obligation is functional in the dying role (Noyes, 1977). The family is not obligated to go beyond its limits of physical, emotional or economic resources.

Finally, the dying person is entitled to continuing respect and status despite his loss of health and function. His dignity is maintained by those caring for him so long as he meets the obligations of the dying role.

Signs of confusion between the dying and sick roles are easily identified. Clearly a person needs knowledge of his illness and prognosis if he is to fulfill the obligation of the dying role. Physicians, and medical professionals in general, must communicate openly with the patient. The "conspiracy of silence" that often surrounds the patient must no longer be maintained by the family, community and the patient himself.

Another sign of confusion between the roles is the tendency to care for dying persons in hospitals. These institutions are primarily oriented toward diagnosis and treatment. Persons in need of support and maintenance type of care are looked upon as a burden. It is apparent that better care of those who are dying could be provided elsewhere.

The fact that dying persons have not been held in high esteem by our society may be a reason that the dying role has been avoided in favor of the sick role. Attitudes must begin to change before the right of the dying person to unchanged status or evaluation within the community is fulfilled.

A tentative but noteworthy distinction can be made of death in modern medical care. There are technically three categories of death: clinical death, biological death and social death. Clinical death is defined by the appearance of "death signs" upon physical examination. Biological death is the cessation of cellular activity. Social death is described by David
Sudnow as a phenomenon incorporating the process of mutual disengagement and rejection by which the human being as a member of society seems prone to take his leave from the land of the living. More specifically, social death refers to the individual who is treated essentially as a corpse, though he remains still clinically and biologically alive (Cohen, 1979).

The concept of hospice care seeks to merge these three categories into one simultaneous moment that culminates many years and months of real living. Hospice attempts to minimize this phenomenon of social death, substituting care and attention for the abandonment and isolation common in the hospital setting.
CHAPTER II

THE CONCEPT

Care of the dying represents a significant gap in our health care system. This gap exists partly because acute-care hospitals are ill-suited to meet the physical and emotional needs of the dying, who must watch their own deterioration and face the rapidly approaching moment of death. Such institutions are geared instead to cure patients and send them home as quickly as possible. They are motivated to prolong life rather than to prepare a patient for death.

Hospice, in contrast, treats the symptoms rather than the disease. The care includes comprehensive treatment of the physical, emotional and mental symptoms. It is the disease of dying that hospice care seeks to eliminate through control of the symptoms.

In a general hospital, the staff pursues four basic goals: investigation, diagnosis, cure and the prolongation of life (Cohen, 1979). Hospice goals are markedly different. In contrast to traditional medicine, a major aid is the palliation of symptoms so that patients can live out their lives as comfortably and meaningfully as possible. Hospice seeks to accomplish these four basic goals for dying people: relief from the distressing symptoms of their disease, the security of a caring environment, sustained expert care, and the assurance that they and their families won't be abandoned (Cohen, 1979).
For most people the classic goals of the health-care system are appropriate and the mainstream of medicine must continue in this direction. However, we must realize that for some people this orientation is not appropriate, that a different care plan is required for those for whom cure is no longer a possibility. It is for those people that hospice is designed.

What is Hospice?

According to the Oxford English Dictionary, "hospice is a house of rest and entertainment for pilgrims, travelers, or strangers...for the destitute or the sick."

The Latin word hospes means both host and guest. This double meaning draws attention to a process, an interaction between people, a simple and mutual value judgment of caring. In terms of our modern medical model, it is interesting to examine the eventual development of the word hospes to hospitium (the French derivation of a place in which to greet a guest), and then 'hostel', hotel-Dieu, and 'hospice'; it is also the root of such Anglo-American words as 'host' and 'hostess', 'hotel', 'motel' and, of course, 'hospital' and 'hospitality' (Cohen 1979). One may discern a subtle shift in values and the essence of human relationships evolving in the development of the language over the years.

The idea of hospice dates back almost 2000 years ago to a place founded in the port of Rome by a disciple of St. Jerome named Fabiola. He cared for pilgrims returning from Africa. A magnificent hospice named Turmanin also operated in AD 475 in Syria. The idea can also be traced back to the rescue attempts and ministrations of the St. Bernard
monks in the Alps and to the Benedictines and the White Cross Knights of the eleventh century. In medieval Europe, many hospices were on record. In England, some 750 were counted at a time of minimum population. Major cities and towns across Europe as well as monastic hermitages in wilderness areas and mountain passes operated hospices for travelers on their way (Cohen, 1979). It was a natural thing in those days to view death as a venture, for life was a journey -- a pilgrimage. Man did not expect to live forever in those days before the Renaissance.

Hospital is also anciantly related to hospitality, a connection seemingly difficult to relate in meaning alone. The ancient hospice serving suffering pilgrims was very different from the modern hospital. It offered an open door to anyone needing care, protection, fellowship or refreshment -- anyone in need of hospitality. It welcomed not only the sick and dying, but the needy poor, the orphan, the hungry traveler or the leper. It did not proclaim or strive to be a place to cure all but a place where comfort was offered to those in need.

It is curious that these words have come to be dissimilar in the modern context. In these times of economic and world crisis forcing the re-examination of material values as well as renewed spiritual questing, it is no coincidence that hospice is one old idea whose time has come again. Hospices are again appearing on the scene and are aided by every advantage of modern medicine, psychology, and clinical pharmacology. With all this technology on its side, hospice concentrates on serving the dying individuals, their families, and their friends to form a total caring community.

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Philosophy of a Hospice Program.

The philosophy, as originally stated by the National Hospice Organization is:

Death is a universal fact of life and, whether or not it is accompanied by disease, dying is a normal process. We believe that every person is entitled to participate fully in this part of life in order to prepare for death in a way that is personally satisfactory.

Hospice, as an option in the medical care system, exists not to postpone death but, with special skills and therapies, to help the patient and family live as fully as possible. Death is not denied, but life is affirmed and lived until death comes.

We believe that we are all dependent on one another. Therefore, it is crucial, in the last few months of life, to help develop a caring community that can provide comprehensive services to patients and their families.

(NHO, 1978)

It is also a basic philosophical tenet of hospice that it is the patients themselves who can most adequately express the type of care they need.

It is not only the patients who are in need of help, though. The entire family, not just the patient, must be the unit of care. Illness, whether terminal or not, or death affects the family in a great many ways. They must have help in coping and adjusting to a life that has changed.

The major goals of hospice care are aptly phrased by the Connecticut Hospice, Inc., the first hospice established in America and are concurrent with the basic philosophy. The goals are to:

Provide physical and psychological care for the patient suffering from an illness diagnosed as terminal,

Care for the families of dying patients during illness and bereavement,

Provide a support system to help people live effectively in the face of impending death,
To provide better care at less cost than present health care services.

(Lack, 1976)

An emphasis of hospice care is to provide complete services to a patient wherever he wishes to be. The hospice program would support a patient's wishes to return home and if he has no home, the hospice inpatient facilities, if available, would attempt to provide a homelike atmosphere for the patient. The home symbolizes a place of rest and comfort where a person can be at peace and master of his life. If going home is not possible for any reason and hospice in-patient facilities were not available, hospice staff members would attempt to provide services in the hospital or nursing home.

Organization of a Hospice Program.

The care of dying patients, or terminal care, a more modern term, is not new. All the work done previously in the care and comfort of the dying should be developed and extended -- not dismissed. Terminal care should become a process of excellence in any system through which it is delivered. There are, however, certain characteristics of a terminal care program that are essential before the term 'hospice' can be used to describe it. These characteristics are not legally set forth but are prescribed by the National Hospice Organization. Hospice is a system of health care delivery with clearly identifiable elements. These elements are:

a) Physician-directed services
b) Control of symptoms (physical, social, psychological, spiritual)
c) Provision of care by an interdisciplinary team
d) Services available on a 24-hour-a-day 7 days-a-week basis with emphasis on availability of medical and nursing skills
e) Patient/family regarded as the unit of care
f) Bereavement follow-up

g) Utilization of volunteers as an integral part of the interdisciplinary team

h) Structured staff support and communication systems

i) Patients should be accepted to the program on the basis of health needs, not ability to pay.

(Lack, 1976)

Physician-directed services

The hospice program of care usually is directed by a physician for two reasons: first, symptom control, the focus of hospice care, is a medical concern; and second, a medical director is best able to generate understanding and support for the hospice concept among other physicians (Plant, 1977).

It is the major function of the physician to assess the patient's overall condition and prescribe symptomatic care and medication. He or she must work closely with other staff members because of concern for the whole person whose needs range beyond the physiologic and biologic (Rizzo, 1978).

Physicians are trained and expected to do everything possible to save a person's life. They utilize the most modern machinery and techniques for diagnosis and treatment in order to preserve life. However, there is nothing in the scientific training of physicians that adequately equips them to deal with questions of ethical or human value. Therefore, one may ask: Should physicians alone make all decisions regarding the care of the dying patient, the course of treatment, and the place where treatment and care shall be provided?

Doctors must learn to cope with patients as human beings rather than disease entities and not look upon death as a failure of their omnipotence. Terminal illness should not be regarded as an intrusion into life.
It is part of life and can be a time of growth for all concerned. They must learn not to be afraid to become emotionally involved with their patients. If they are unable to do this by reasons of personality or pressure of other work, then it is their responsibility to provide direction to other personnel who can give the patient a chance to grow.

Terminal patients and their families consistently report their feelings of medical abandonment (Lack, 1977). There is a time in a patient's illness when the health-care professionals begin to feel that there is nothing more that they can do to cure the patient, and it is the loss of the interest of their doctors that patients fear the most. When a patient elects to remain home for his last weeks, this decision frequently cuts him off from effective medical care because many physicians do not make home visits. Many patients do not see their doctor for long periods of time and if they struggle to his office are frequently seen by a resident while the doctor sees patients who can be cured (Lack, 1976). It is vital to the psychological well-being of the patient with terminal illness that the physician is a key figure in the care he receives, and it is equally important that the patient receives effective medical care from his doctor to make his last days more comfortable.

In hospice care the physician is expected to take primary responsibility for the patient's care including making frequent home visits and monitoring of all physical care given to the patient. In some programs of hospice care, medical directors are employed that assist the physician or take over the patient's care if the personal physician can or will not.
Symptom control

In the care of the terminally-ill, by far the most critical symptom that must be relieved is pain (Cohen, 1979). According to Abraham Maslow's hierarchy of needs, a person's physical needs must be met before he can face emotional or psychological needs. This is where symptom control has its strength. If the dying patient is relatively free of pain, he can live each day to its fullest. No patient should want to die because of the pain he is suffering.

Anyone concerned with service to the dying should place physical comfort of the patient high on the list. Counseling a person lying in a wet bed is ineffective, to say the least. A certain amount of interdisciplinary role blurring may be necessary to ensure patient comfort at all times. Everyone in contact with the patient should be knowledgeable of the elements of pain control, observant, and conscientious in reporting symptoms to the team.

There exist four types of pain that must be dealt with by the caregivers. They are social, psychological, spiritual and physical pain which make up the total pain of a dying patient (Cohen, 1979). The different types are interwoven so subtly that it is difficult to distinguish or treat them separately. All must be understood and addressed, however, before the pain can be brought under control. Since all are so interrelated, therapeutic activities and distractions may help alleviate a large part of the pain.

Robert Woodson states,

Social pain may be defined in two ways: 1) it may be defined as a patient's "mild-to-severe discomfort" with man's inhumanity to man -- a common theme in history of all technocratic civilizations, or 2) it may be defined as simply a patient's discomfort with the level and intensity of his or her interpersonal relationships,
especially if one is in the process of dying...It is important for the dying patient and his family to finish any unfinished interpersonal business including learning to say goodbye to one another for the last time (Cohen, 1979).

Hospice seeks to provide quality social interaction. Talk is therapeutic; and caregivers, other patients, families, and volunteers can contribute to the patient's social life by sharing some of the pain. By preventing social pain from consuming the patient, the caregivers provide opportunity for the grieving process to begin before the patient dies.

Woodson has defined psychological pain as:

The dying patient experiencing "psychological pain" is frequently the frightened or anxious patient, the lonely or depressed patient, or the hurt and angry patient. As he begins his final stage of growth by anticipating his own mortality, the terminally ill patient often endeavors to "set things in balance" by attempting to maintain a kind of psychological homeostasis of equi-finality with his inner self and his perceptions of the immediate environment. This imbalance or loss of control over his or her life, especially the now "new" experience of learning how to die, usually calls up a repertoire of coping behaviors aimed chiefly at reducing the stresses of dying and at regaining control over one's life...Thirty minutes of cathartic grieving with a family member, nurse, or skilled therapist can have profound positive effects on a dying patient's depression and concomitant anxiety (Cohen, 1979).

Again, Woodson has said that "to date there is no clear-cut definition of what constitutes 'spiritual pain' particularly as it relates to the dying. Spiritual pain is as different for each patient as is the patient's specific religious, transracial, or cultural background" (Cohen, 1979). Yet we know spiritual pain does exist, and though it manifests itself differently in each patient, counseling by trained clergy or other counselors may relieve it.

The most debilitating of the four kinds of pain is physical pain. There are two types of physical pain: acute and chronic. William Lamers, Medical Director of Hospice of Marin in California, feels that physicians
are well-trained in treating acute pain, but that they are untrained in treating chronic pain. In Walter Norman's opinion, "our major concern has to be focused on the control of pain rather than the alleviation of pain" (Cohen, 1979).

Cancer pain seems to be without purpose. It seems to have a rather sinister meaning. Most people who awake in the morning with a stiff neck assume they have left a window open and slept in the draft. A person with cancer who awakes with a stiff neck assumes that the malignancy is spreading. Pain in terminal illness is perceived differently and must be dealt with differently.

Narcotics, regularly administered, are the most effective means of controlling severe pain (Cohen, 1979). Parker Rossman states,

At the heart of the hospice concept is a view of pain control which runs counter to the way a general hospital nurse is taught -- i.e., to withhold pain medicine until the patient demands it -- or the hospital procedure by which a patient is given pain medicine on a fixed routine of every four hours even though he or she may begin to suffer serious pain within three hours. The hospice staff... assume that once it is definite that a person is dying, then the comfort of the patient takes precedence. Instead of waiting until the patient is miserable with pain to give relief, instead of waiting for the patient to demand the medicine because of his or her suffering, the hospice staff anticipates pain and gives the drug before the pain occurs, so that the patient never experiences any serious pain at all (Cohen, 1979).

For the dying there is no maximum dose of a pain killer. The fear of addiction seems irrelevant. Special mixtures, developed by pioneers in hospice care, have proven to be effective in controlling severe pain while allowing the patient a normal affect (Melzack, Ofiesh, Mount; 1976). Examples of such mixtures are the Brompton's Cocktail and the Hospice Mix which consist of varying amounts of morphine or heroin (illegal in the U.S.), alcohol, cocaine and flavorings. These are to be taken
orally on a regular basis. LSD has also been used but its effectiveness is not yet fully determined.

There is never a time when "nothing more can be done" for a person diagnosed of a terminal disease. Primary and secondary symptoms can and must be relieved in order to allow the patient to live each day to its fullest.

If people are cared for with common sense and basic professional skills, with detailed attention given to self-evident problems and physical needs, then patients and families can cope effectively with many of their emotional crises of living those last few months with the dying person.

**Interdisciplinary team**

The management of the dying must be a team concern. The team includes the dying patient, his immediate family, his doctor, the chaplain, the nurses, the social worker, the volunteer, and other health-care staff. Continuity of management forms an important part of the total care. Interdisciplinary care must not be a synonym for fragmented care in which the bewildered patient does not know who is in charge or who is dealing with which problem. Real team work mandates that interdisciplinary staff sit down together at regular conferences to work out a plan of care for the patient/family and to learn each other's languages.

**Services available on a 24 hour basis**

Emergencies do not happen from 9 a.m. to 5 p.m. as many people would like. The patient and family may need special help at any time and the staff and volunteers must be responsive to this need. Fear and anxiety may be the only real problem but must be handled. Provision of emergency
support that the family or patient may need offers security and the emotional strength needed to continue.

**Patient/family as a unit of care**

According to Dr. Saunders of St. Christopher’s in London, "Nothing that we do should serve to separate someone who is dying from his family. There may be moments of difficulty or even despair, but it is of paramount importance that they come through to the end together. The journey itself may ease the next states for those who have to go on living afterwards" (Lack, 1976). A terminal illness is not like an acute illness. In an acute illness, although the short term stress may be great, there is hope and anticipation that full family functions will be restored and life will go on as it did before. In a terminal illness, every member of the family is pulled in and affected by the reality of death. Adjustments to living without the patient must begin before death, as functions previously fulfilled by the patient have to be taken over by other members of the family. The family must be involved from the beginning for the patient’s benefit as well as their own.

Many family members deny their own needs because of the demands of caring for the sick person. However, their own needs still exist: they work about them, and eventually feel neglected, and may resent the patient for drawing attention away from themselves. Families can cope with this resentment and manage for a much longer period of time if they have professional support immediately available to them.

**Bereavement follow-up**

A hospice program provides emotional support for the surviving families during bereavement. Care does not stop with the death of the patient.
The family is continually visited on a scheduled or emergency basis at the point of death and on into the mourning period. Families require assistance as they endure the psychological suffering caused by the separation. 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 to 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 (Craven and Wald, 1975).

Volunteers

Lay volunteers can be used to help the family with day-to-day tasks of running a household as well as other important duties. The volunteer is also uniquely able to help the patient maintain or re-establish his sense of self-worth. The dependency and lack of independent functioning created by a disability eats away at a person's self-esteem. The withdrawal of health-care professionals, as they try to cope with their own feelings of inadequacy, reinforces the patient's diminishing sense of personhood. The volunteer can counteract this demeaning process by forming a close friendly relationship with the patient. Volunteers are given a basic training course and are carefully screened before working on a one-to-one basis with patients. They are also advised not to try to fulfill a counselor's role. They come from all professions: i.e.,
lawyers, nurses, dieticians, accountants, mothers, etc. Their special value is as a persons with whom the patient can identify. He sees them as "people like myself."

**Ability to pay**

Patients are to be accepted on the basis of health-care need, not on ability to pay. No British hospice discriminates against patients because of their financial status (Cohen, 1979), and American hospices must also strive to uphold this high standard of care. We cannot avoid this responsibility in this area by reference to socialized medicine in England. Most of the hospices in Britain are not under the National Health Service. They are financed by a combination of charitable donations, patient contributions, and government reimbursement (Lack, 1976).

**Structured staff support**

Strong support systems must be developed for the interdisciplinary team members. This team is possibly the best group within which to establish supports. Support systems may consist of sharing groups where the members of the staff can blow off steam and can share how they feel about what is happening to this patient. Volunteers may need to form a separate group for more individual needs characteristic of their position. Most important is the availability of a specified staff member that can help the team members in moments of crisis.

**Hospice Development in U.S. and Britain**

Approximately thirty hospices have appeared in Britain in the last 10 years (Kolbe, 1977). Two of the largest and oldest hospices located in London, St. Joseph's and St. Christopher's, provide home care services in addition to the usual British form of in-patient care.
Hospice is beginning on the American continent. The first hospice to be established and now providing both in-patient and home care, is the Connecticut Hospice, Inc., formerly Hospice, Inc., located in New Haven, Connecticut. Facilities or programs are now operating on both coasts. There are over 200 hospices established or in development across the United States at the present time (Cohen, 1979).

There are many forms of service that hospices in the U.S. take. Some of the hospices are actually units within hospitals giving hospice-like care as opposed to the traditional type of care. St. Luke's Hospital in New York City and the Parkwood Community Hospital in Canoga Park, California, are two examples of this type of service. In St. Luke's Hospital, there is no hospice bed area. Hospice patients are found throughout the institution where teams including a physician, nurse, psychiatrist, social worker and chaplain, give them special attention. The patients are given more freedom and are exempt from usual hospital visiting hours. The patient's physician usually retains primary medical responsibility. A supporting home care program providing continuity of care to the patient whether in the hospital or home is also operated by St. Luke's.

At Parkwood Community Hospital, a consolidated unit is in operation. It functions as the equivalent of a separate hospital department having its own staff, outside entrance and family room. Similar units in other hospitals are sometimes called palliative care units or PCU's. The medical director of the team assumes the medical responsibility for patients admitted to this unit. Direct nursing care to hospice inpatients ranges from 8 to 12 hours a day, as compared with the typical 5 to 6 hours a day for general hospital nursing care (Plant, 1977).

Many hospices provide home care programs in addition to in-facility
care to allow the patient the choice and freedom of residence in this latter stage of life. An additional example of a model hospice serving people in the facility or at home is the Connecticut Hospice, Inc. Hospices with home-care/in-facility care provide strong continuity of care to the dying patient. Home-care techniques of comfort are continued in the hospital. The staff supplements each other's care and works closely together in following the patient and the family wherever they are.

Another form of service is affiliation with a hospital and a physically separate facility. Riverside Hospice in Boonton, New Jersey, was set up as a hospital affiliate for tax and other financial reasons but remains physically, managerially, and financially distinct. Physician involvement is assessed by a meeting with the hospice's medical director and the patient's physician. A home-care program also supplements the hospice care (Cohen, 1979).

The day hospital concept, which has existed in England since the early 1940's, was introduced later in Canada and recently has received attention in the United States (McNamara, 1978). Provision of day care with emphasis on personal care, professional health-care staff, and therapeutic activities provide continuing care and support to permit terminally-ill patients to remain at home. This type of care has been successful for the elderly and for the mentally handicapped; and with special emphasis placed on hospice, this mode of care can provide an added plus to available and quality hospice care.

Facilities originally designed for the care of the terminally-ill before the hospice concept was formalized are now incorporating many of the hospice specifics into their service as well as transmitting valuable
information to hospices in the development phase. An example of such a facility is Calvary Hospital in New York City. Calvary Hospital is devoted solely to the care of the terminally ill. Patients are admitted based on diagnosis and immediate need. Upon admission, each patient is assigned a personal physician who is responsible for the patient's care on a continuing basis. The staff promotes a close physician-patient relationship. Calvary also has a professional training program in the care of those with advanced cancer (Markel, Sinon; 1978).

Hillhaven Hospice in Tuscon, Arizona, offers a comprehensive program of care incorporating home care, in-patient, and day care components. Hillhaven strives to provide services very similar to the British tradition of hospice. In-patient care essentially services three purposes: 1) temporary or intermittent care in order to control symptoms or modify the treatment regime, 2) respite care of a short-term nature in order to relieve the family, and 3) terminal care when care in the home is not possible (Hackley, 1977).

Many other hospices are developing in a home health agency framework and are providing hospice services to the patient at home. Services are provided by the general agency staff with certain components given by specially trained hospice staff. The personal physician also retains primary responsibility for the patient's care. Efforts are made in a setting such as this to provide services to the patient wherever he may be, but these services are usually not formalized in other settings so efficiency of hospice care is reduced. Hospice of Helena is an example of this type of service delivery.

Other hospices consist of a group of compassionate individuals who are professional and lay members of the community in which they live.
The structure of such a hospice group is usually informal and is limited to serving only those people who are knowledgeable of them and seek their help.

Reimbursement.

Third-party payment is crucial to hospice development -- to its survival. Today more than 95 percent of the population in the U.S. is covered by some form of health insurance (Cohen, 1979). This includes both federal, state, and local government programs as well as private insurance companies.

At present, laws governing reimbursement policies discriminate against the dying by providing funding for cure, not care (Cohen, 1979). Thus, to change reimbursement policies of third-party payers, laws must be changed. Hospices contained within hospitals have an advantage that their patients are not always diagnosed as dying and are entitled to benefits of third-party payments without strict limitations. The issue of reimbursement is closely tied to that of licensing -- a function of state government. Licensing goes hand in hand with regulation. Regulations are very specific for facilities or agencies that are licensed and since hospice services are not yet formalized by regulation, they cannot be licensed, and further, are not recognized by the federal government for reimbursement. A few established hospices are promoting their licensure as hospital-hospice in order to assure reimbursement (Plant, 1977).

A central component of hospice care, that the family and the patient are the unit of care, is foreign to all third-party payers. Therefore, bereavement care and many social work and counseling services of a hospice program cannot be compensated for. Also, Medicare regulations require a three-day hospital stay, thus complicating or nullifying the hospice
approach of transfer from home to hospice as the patient's condition changes.

Because quality care may follow closely to reimbursement, less reimbursement for a terminal-care bed than for an acute-care bed could conceivable mean a continued low priority for hospital-based hospice care unless the hospice patients are hidden within the general population (Cohen, 1979).

Some private insurance companies are engaging in pilot projects for hospice care reimbursement. Blue Cross/Blue Shield of Maryland, for example, is providing benefits for a two-year period to cover such services as physician home visits, medical social service, nutritional guidance and bereavement evaluation visits. Although the benefits are at a minimum, it indicates a beginning awareness (Hospice Letter, 1979). Connecticut General Life Insurance Company has become the first life insurance company to offer hospice benefits to its subscribers at no additional cost. This provides for medical and social services for terminal patients receiving home care. This company has enacted and amended legislation for Connecticut residents concerning hospice insurance policies (Hospice Letter, 1979).

A survey done by Kenneth P. Cohen (1979) of insurance companies in the U.S., Canada, and Puerto Rico ascertained that few, if any, policies provide hospice benefits as a defined policy benefit. Generally, the only services for which hospice receive insurance reimbursement payment are all medical nursing health services in which there is a "laying on of the hands."

On October 3, 1978, HEW Secretary Joseph Califano announced that the Health Care Financing Administration (HCFA) would be conducting
demonstration projects with organizations now providing hospice services. According to HCFA, waivers of Medicare coverage and reimbursement requirements and exclusions will be granted...to permit payment for hospice services to patients with a life expectancy of six months or less (Cohen, 1979). Of significant importance is the fact that the federal government recognizes the inadequacy of reimbursement policies for hospice patients. At present, these demonstration projects are not yet completed so no cost results can be ascertained, but the issuance of the waivers is a step forward.

Cost.

Health care delivery appears to follow the dollar and that dollar is heavily invested in the traditional medical model -- cure -- and also is invested in the traditional institutions: i.e., hospitals, nursing homes. There is limited financing of services provided in the home, particularly to the dying.

Edward Dobihal (1974) feels strongly that the hospice system of care offers a less expensive alternative to care that is now primarily based in acute general hospitals. It seems reasonable that the type of care which does not require expensive and elaborate tests and equipment should cost considerably less than the care given in acute-care hospitals.

According to Elisabeth Kubler-Ross, when terminal patients are treated in hospitals, costs can run about $300 per day, but at home, using the Brompton Cocktail for pain control, medication costs run about 80¢ per week! (Cohen, 1979).

In this initial stage of development, the cost issue is unresolved. Many studies are presently being conducted on many variations of cost in hospice care but few definitive conclusions have been reached.
Leda Judd advocates that cost effectiveness must be addressed at two levels: 1) the comparative costs between conventional treatment and hospice treatment as a whole; and 2) a comparison of costs between models of hospice care (Cohen, 1979). Hospice home care, requiring less staff time, would be less expensive than free-standing hospice facilities or in-hospital hospice units.

Even though hospice care is not elaborate and seeks to provide a homelike atmosphere, it should not be concluded that it is entirely cheap. Nursing staff-patient ratios are much higher in hospice care than in conventional hospital settings. St. Christopher's Hospice in England has a 1.25 to 1 nurse/patient ratio to provide the physical and psychological care required (Rizzo, 1978). Complicated equipment and tests are not used in hospice care, thus reducing cost; but at the same time, counseling and other forms of assistance are provided to the family that are not provided in the hospital setting and which elevate the costs.

The cost of home care has been estimated to be about 50 percent less than that of in-patient care, with out-patient care cost falling somewhere in between. This has been translated by an Advanced Health Systems Report as a potential savings to society of 7.4 billion dollars annually (Cohen, 1979).

Legislation.

There are many issues indirectly related to the hospice concept, for example, the definition of death, euthanasia, the right to die, and suicide, that have been addressed by attorneys, legislators, physicians, philosophers, and theologians for many years. The debate continues, and because of the high emotion surrounding these problems, solutions will very
probably be slow and deliberate in coming. A few states have taken legislative action in some of these areas.

Eight states (California, Oregon, New Mexico, Nevada, Arkansas, North Carolina, Idaho and Texas) enacted right-to-die laws in 1977. Twenty-seven states have right-to-die bills pending before their legislatures (Cohen, 1979). These laws vary somewhat from state to state but all prescribe a procedure whereby people may provide in advance for the withholding or withdrawing of medical care in the event they should suffer terminal conditions brought about by illness, disease, or injury (Cohen, 1979). The person must formally execute a directive in the form and manner prescribed by law. If all requirements are met, the act relieves physicians and other licensed health-care personnel and health-care facilities from liability, criminal prosecution, or charges of unprofessional conduct (Cohen, 1979).

An example of a directive for the right to die is the "living will." It is not legally binding but an assumption is made by the persons signing it that the caregivers will feel morally bound to abide by its provisions at the appropriate time. This is not the legal form required by any of the eight states with right-to-die laws but it is similar.

It is no longer possible for physicians to pronounce a patient as dead four to five minutes after the heart and breathing have ceased. Because of modern technology, life can be maintained for an indeterminable period of time. Now that medicine has progressed into the organ-transplant era, the definition and determination of death from a medical and legal point of view has become a necessity. The exact point of death is not so important as the certainty that the process is irreversible according to Charles L. Hudson (Cohen, 1979). The pronouncement of death on the basis
of irreversible cessation of all brain functions has become common.

Since October, 1977, 18 states, including Montana, have enacted a statutory definition of death. All 18 recognize that death may be pronounced on the basis of irreversible cessation of brain functions, but none describe in detail the specific criteria for determining brain death (Cohen, 1979).

To discern the scope of current legislation directly relating to hospice care, Kenneth Cohen conducted a survey in 1978 to determine what legislation pertaining to hospice, terminally ill and related topics exists or is pending at the state level in the U.S. and at the provincial level in Canada. The most significant survey finding was that not one of the respondents had any legislation in existence relating directly to hospice. California had a bill pending before the legislature requiring the establishment of at least two pilot hospice projects featuring MediCal (Medicaid) reimbursement. New York also reported a similar bill pending. Conclusions will not be available until 1981 if these projects are begun (Cohen, 1979). No legislation regarding terminally-ill patients and other related topic was reported in the U.S. or Canada.

Since the completion of the survey, California and New York have enacted the previously mentioned bills into law.

Not everyone can or should die at home, but currently, care for the terminally ill in most hospitals and nursing homes range from inadequate to fair. Many people prefer to die at home, but our modern society in a sense of avoidance or denial of the reality of death has assumed that the dying would be better serviced in a general hospital where all energies are focused on curative attempts to prolong life, rather than on palliation, which is the emphasis of hospice care. If our society would
but face the reality of death and the needs of the dying patient and his family, hospices would flourish and continue to provide excellence in fulfilling care and comfort of those in the last stage of their journey through life.

The famous psychologist Abraham Maslow aptly summed up hospice care in making the following observation shortly before his death in 1970. After his heart attack, Maslow referred to his "post-mortem life" which he keenly enjoyed: "If you're reconciled with death or even if you are pretty well assured that you will have a good death, a dignified one, then every single day is transformed because the pervasive undercurrent -- the fear of death -- is removed" (Hendin, 1973).
ROADBLOCKS TO THE HOSPICE MOVEMENT

Most roadblocks to the development or change in a social organization stem from attitudes. Attitudes toward today's health-care system must be modified in a few areas before the hospice movement and design is complete. Attitudes of health-care professionals, consumers of health-care, legislators, bureaucrats, fiscal decision-makers, health insurance policy makers, and society at large are the key elements in the success or failure of hospice development.

In May, 1977, the Third National Hospice Symposium was held in California. Out of the symposium came a listing of nine major obstacles to hospice development. They are:

1) acceptance of the hospice idea in a death-denying culture
2) ignorance of the hospice care process
3) need for money
4) regulatory agencies
5) statutes and regulations
6) the emotional issue of euthanasia
7) the internal environments of hospice
8) organizational structure
9) the team need

(Cohen, 1979)

One could easily add many items to this listing. Two very important concerns may well summarize those many elementary items.
These two additional listings are attitudes and the type of support systems available in modern American society.

Acceptance in a death-denying culture

Death evokes many fears; consequently, many refuse to acknowledge death, particularly their own death. If one ignores it, maybe it will disappear.

Yet, though death has long been a taboo topic it is beginning to be the center of public and professional interest. Many writings are currently available with multitudes more being published daily. There is a danger in this suddenly increase in interest in a long taboo topic. Too often such topics become "fads," are highlighted for a brief period of time, and then interest shifts to new fields of exposure (Dobihal, 1974). Death and dying and, more specifically, hospice, are too important to be relegated to that usual process.

Attention to this kind of care for terminal illness does not negate acute treatment, chronic or rehabilitative medicine, or efforts to discover cures for various diseases. It is time, however, that we stop denying the need for terminal care, and continuing the myth that somehow scientific medicine will defeat death as the natural end to our lives (Dobihal, 1974).

Ignorance of hospice

Generally, the hospice concept is unknown in the United States. The general public needs to be educated about the hospice care process.

Many health-care professionals are not aware of the hospice philosophy and also need education. The training of physicians and other health-care personnel has been deficient in the area of death and dying (Cohen, 1979).
These skilled professionals need to be educated about the special needs of the terminally ill so that their appropriate abilities can be effectively utilized.

At present, there is an overlap of hospice functions. Many home health agencies provide homemaker and nursing services but many do not provide the counseling and symptoms control by hospice programs. Many physicians claim that hospice is not new, that hospitals or nursing homes have provided these services all along (Cohen, 1979). They may be correct to a point, but most of these institutions do not concentrate on caring for rather than curing their patients.

Although the media can serve as an invaluable asset in education, it tends toward sensationalism. Any new programs to improve the care of the dying should be undertaken with caution lest they make matters worse instead of better (Noyes, Clancy; 1977). Much of the current media emphasis on death and dying is backed by emotionalism and based on individual experience. Such a thrust makes the public aware and ready for change but does not point to the direction that change should take. Improved care for dying persons can begin within the existing health system through the application of proven practices of care and delivery (Noyes, Clancy; 1977), providing the public with a sound base for learning of hospice.

Need for money

Capital is needed to build hospice programs. Hospice demands continuity of care and, thus, demands continuity of financial support. Policy changes must be encouraged in governmental agencies as well as in private insurance agencies.

Eventually, hospices should become financially semi-independent.
through income of memorials and community donations. Initially, though, money is needed to educate society and the personnel to provide hospice care. Too little money will threaten the existence of hospice; and money improperly used will threaten the credibility of hospices as providers of necessary health care, leading ultimately to their demise (Cohen, 1979).

**Regulations**

Of growing concern to those of us who understand the essential elements of the hospice program is the attempt by some to fragment and jeopardize the integrity of the hospice program through either substandard and/or partial implementation (Dunn, 1977). This threat to hospice can only be reduced by regulating the industry to ensure quality care.

At this time, there is no knowledge of any states having regulations covering hospice care. Hospices do not fit into any existing category. They are not hospitals, nursing homes, or home health agencies, yet they may be functioning as parts of all three types of organizations. The question of licensure and certificates of need must be determined by each individual state. Statutes must be enacted by the state to provide legal frames of reference from which the regulatory bodies can then prepare regulations and licensing codes to which hospices can be held accountable (Cohen, 1979).

At present, hospice development appears to be eclectic and free of boundaries. This free enterprise route may provide a healthier environment for quality hospice development than governmental interference could.

At the moment, planning for hospice in health-care policy is almost nonexistent (Cohen, 1979). This can be attributed to the lack of knowledge of hospice among the general public and health systems agency members.
Hospice needs to be considered in national planning. When the public becomes aware of hospice, legislation and policy making will follow.

Euthanasia

Hospice is not euthanasia. Hospice is a caring community dedicated to providing comfort and loving care to terminally-ill people and their families. "Because of a lack of caring in our society, some people die in distress and that same lack of caring leads people to suggest euthanasia as a solution," says Richard Lamerton, Medical Director of St. Joseph's Hospice in London. He also aptly sums up the hospice view of euthanasia this way:

To fail to provide for the needs of the dying is to fail in a basic duty. The self-evident requirements of a dying man are to have his symptoms relieved and to be allowed to die with dignity and peace of mind. If we evade all the difficult problems he presents and just kill him, we have failed. Whether such euthanasia were voluntary or not is irrelevant. It is our duty so to care for these patients so that they never ask for euthanasia. A patient who is longing to die is not being treated properly. If we are not treating him properly, the solution is to improve our treatment, not to kill him (Cohen, 1979).

The Internal Environment

The environment of hospice is necessarily related to money. Staff members must be paid; rent, supplies, and other expenses must be paid. Altruism is also a required ingredient but unlike the hospice of the Middle Ages, the modern hospice cannot exist strictly as a charitable program.

The attitude of the hospice care giver is crucial. Positive attitudes will undoubtedly aid the development of quality care, while negative attitudes and disagreements about what can and should be done for terminally-ill patients and their families can only impede progress.
Organizational Structure

Though there are a variety of organizational models and a number of combinations, newer and possibly better structures will surface in the future.

Any new part of a health care system does not effectively work in isolation but if it is to be most useful to the person in need, it must be integrated into the total fabric of the health care system of the community (Dobihal, 1974).

Persons interested in developing a program of hospice care must keep an open mind to all existing models and to those which might appear in the future so that they can utilize the best features of each tailored to their own geographical and community resources.

It appears that the hospice movement will provide either a "separatist" or an "integrationist" motif of medical care for the dying, depending on community needs and resources (Krant, 1978).

The Team Need

The interdisciplinary team is a central theme of hospice care. All professional and non-professional care givers must merge their separate talents into a total care program for the good of the patient. In order to develop an effective team, attitudes must change. Professionals tend to view their contributions to the team as superior to that of a lay person. This is not always the case -- often times the volunteer or friend of the patient can lend invaluable insight into that patient's needs and solutions to those needs.

Attitudes

Concern for perceptions and attitudes of society are paramount to the success of any social movement. Attitudes influence every component
in hospice care as has been mentioned in previous subsections. Research in attitudes and opinions of professionals and non-professionals, patients, families, and policy makers are needed before we can adequately assess the roadblocks to hospice development and subsequently remove those roadblocks. It is for this reason that the following section of this thesis deals with the attitudes of one distinct member of the health-care system -- the physician.

Support Systems

The hospice concept of home care is dependent upon a primary care giver who assumes the responsibility of administering daily care and comfort to the dying patient. Without a primary person or group of persons functioning as the patient's support system, hospice care cannot work at home. The patient must then be institutionalized. If free-standing hospices are not available in the community, this means placement in a hospital or nursing home.

In our mobile society, the extended family system has not been maintained to any great degree. It is not often that an individual lives near members of his family. The burden is then placed on the nuclear family to serve as the support system in any circumstance. In the case of terminal illness, the spouse or adult child fills the role of primary care giver. If there is no spouse or children to care for the person, the option of hospice care is not often available to an individual in the U.S.

Prognostication?

What is the future of hospice? This movement is likely to expand at a rapid rate for the next five years or so in the United States. After
that period it should stabilize and become a legitimate part of the health-care delivery system. During the period of rapid growth, a number of opportunists will enter the field eager to make a quick profit. Fly-by-nighters will explore hospice and will fall by the wayside because of mismanagement and poor quality care provision. The diligence and perseverance of conscientious caring hospice operators will survive and grow. Obstacles will be overcome and a firm basis for hospice care will eventually be founded.

As the public becomes aware of hospice and the viability of the concept is demonstrated, legislation will be created providing for quality care and adequate reimbursement policies.
CHAPTER IV

THE SURVEY

Purpose.

In today's health-care delivery system, physicians are among the primary providers. The decisions they make affect the patient's social, psychological and physical well-being. As Dr. F. J. Roberts points out:

I shall define attitude as a settled mode of thinking. I want to suggest that doctors' attitudes to the dying have special consequences for both the patient and the doctor, and that by considering this topic we may be able to change some attitudes so that both our own, and our patient's experiences, are enriched (1978).

For these reasons, the purpose of this survey is to explore physicians' attitudes toward care of the terminally ill, specifically, toward hospice care as an alternative method of health care.

Review of the Literature.

No previous studies of doctors' attitudes toward the concept of hospice care could be located by this author. Two studies of physicians' general attitudes and opinions did prove helpful in establishing a base for this survey. Those studies dealt primarily with the subjects of prolongation of life and general professional values. Some relevant conclusions from those studies are included herein.

A longitudinal survey by Russell Noyes, Jr., M.D. and associates, of physicians' attitudes and practices in the care of terminally-ill patients emphasized the use of life-shortening or -prolonging measures.
The study indicated that more open communication had developed between physicians and their dying patients in the period studied between 1971 and 1976. The isolation and helplessness experienced by these patients may be reduced by this increased communication. Shared awareness of the prognosis may allow the patient to live his life fully until such time as death occurs. The patient who communicates openly with his physician and other health professionals may be motivated to participate in his physical care and thereby reduce some of the helplessness he may feel in the face of death (Noyes, Jochimsen, Travis; 1977).

This increase in awareness of both the patient and the physician may obliterate the previous confusion in social roles. Patients have commonly adopted the sick role rather than the appropriate and distinct dying role. Unfortunate consequences of this confusion have included overzealous treatment by physicians, too frequent confinement in acute-treatment facilities, and stifled communication between dying persons and those who care for them (Noyes, et al; 1977).

Noyes and associates concluded in the research that the current discussion of death and dying seems to affect the care of the terminally-ill patients in a favorable way which, in turn, will foster further discussion on the total care of the patient (Noyes, et al; 1977).

Dr. Jane Leserman (1978) surveyed first year medical students focusing on their professional orientations concerning physicians' relationships with patients. She identified the need to humanize physician-patient interactions and involve patients in health-care decisions. Although the values of students of medicine do not predict their subsequent professional behavior, valuable implications may be drawn.
Dr. Leserman's findings proport two values pertaining to patient involvement in health care. The students placed importance on providing health information concerning diagnosis and treatment to patient including access to the medical record. The students were also critical of absolute confidence in physicians' judgments. Values pertaining to humanizing the patient-physician relationship include an emphasis on the social and psychological factors in health care, including empathy and rapport with patients and a commitment to helping people (Leserman, 1978).

One may conclude from these findings of Noyes and Leserman that physicians are becoming increasingly aware of the patient as an individual and the necessity of not only treating the physical aspects but also establishing strong communication with the "whole" person. One concept that provides care for the "whole" person during a terminal illness is hospice care. Increased awareness on the part of the physician of the needs of the dying patient may well lead them to support the hospice concept of care.

Background of the Study.

In speaking to a variety of health-care professionals in the Helena area, I was impressed with the encompassing concern about the physician's orientation toward hospice care in relation to the success of this model of care in the Helena community. It was felt that without the physicians' support, hospice care could not exist within the community for any extended period of time. The physicians would necessarily provide the legitimate referral for hospice care and also provide continuing support to the patient and the family throughout the process of terminal illness.
Study Distinctions

Three distinctions were made in this study concerning the practicing physician population. The first group is composed of physicians dealing directly with the patient by diagnosing the terminal illness, treating the specific terminal disease and making primary decisions concerning the patient's prognosis and appropriate type of treatment (active or passive) relative to that disease. The second group is composed of physicians who deal indirectly with the terminally-ill patient and whose contact with the patient is not to treat the terminal disease but to provide ancillary health services such as radiology, dermatology, pathology, opthamology, anesthesiology, etc. The third group is composed of physicians employed by the Veteran's Administration Hospital at Fort Harrison, Montana. This hospital services not only veteran members of this community but also veterans from all over Montana. Thus, their direct involvement with the Helena community is limited. At the same time, the VA Hospital could be seen as a community within itself because a comprehensive list of health services comparable to those provided in the Helena community are provided within the complex. Although direct-care and indirect-care physicians are employed at the VAH, this group will be treated as one sample with no further distinctions due to the limited size of the population.

Assumptions

In this survey, hospice care is assumed to be an alternative to hospital or other institutional care. The hospice concept will be initially implemented in this community as a satellite of a home-health care agency and will be available to patients at home and in institutions. The care to institutionalized patients shall be supplemented by the hospice team: that is, they will not provide primary care but shall provide other
elements of hospice care to the patient. Future expansion of hospice services may create a full institutional setting for the dying, but presently, all community hospice services are being provided within a home-health care framework.

Method.

Sample

A stratified systematic sample was selected from each population: i.e., direct-care, indirect-care and VA physicians who are currently practicing in the Helena area. The physicians were stratified into the three areas previously determined, and a systematic sample was drawn for each area from an alphabetized list of physicians. A total sample of 45 was drawn initially out of a total population of 80. Twenty-eight direct-care physicians were selected out of a possible 50 to represent 62.5 percent of the total 80. Ten indirect-care physicians were selected out of a possible 18 to represent 22.5 percent of the total. Seven Veteran's Administration physicians were selected out of a possible 12 to represent 16.25 percent of the total. The percentages relate to the total number in each area as compared to the total population of 80. The sample size was determined by using the following statistical formula:

(Mendehall, Ott, Schaeffer; 1971)

\[
n = \frac{Np(1-p)}{(N-1)B^2 + p(1-p)} = \frac{80(0.5)(1-0.5)}{(80-1)(0.1^2) + 0.5(1-0.5)} = 44.69 \text{ or } 45
\]

N: population size
n: sample size
p: estimate for population parameter
B: error bound
The first sample of 45 yielded the following number of interviews that could not be completed: direct-care, four refusals, four moved; indirect-care, one refusal, one moved; VA, one unavailable. Because the number of incompletes in the direct- and indirect-care areas constituted a significant part of the whole, another sample was drawn continuing the systematic process to equal the number of incompletes in each area. Out of the eight new direct-care physicians contacted, two refusals were noted and one was available. One more direct-care physician was then drawn, contacted, and interviewed, completing a total of 25 out of 28 interviews or 89.3%. One interview was not counted as the physician expressed his opinions freely but did not answer the specific questionnaire items.

Out of the three new indirect-care physicians contacted, one refusal was noted yielding a final response rate of 9 out of 10 or 90%.

One VA physician was unavailable, and no further sampling was done because of the time element involved in this study. Six out of seven VA physicians were interviewed to provide a completion rate of 85.7%

Thus, the final sample included 40 physicians -- 25 direct-care, nine indirect-care and six VA physicians.

Tool

A questionnaire was developed through interviews with professionals and para-professionals in the health-care field as well as educational professionals who officially served as advisors to this thesis. These professionals evaluated the questionnaire for clarity, specificity, and wording. The tool was designed to provide an outline for a personal interview with each physician in the sample. Selected physicians were
first contacted by letter explaining the purpose of the survey and asking permission to make an appointment for the interview. The physician's office was then contacted and an appointment made or a refusal to be interviewed noted. The time requirements for the interview ranged from five minutes to one hour with an average time of 15 minutes.

Refer to the appendix for a sample of the interview form including the definition used.

**Analysis**

Means were calculated on items lending themselves to central tendency measurement. Yes and No items as well as Likert-type responses were reported by number of respondents to each question. Responses to two questions included in the original questionnaire shall not be dealt with by the researcher at this time. They are: the number of patients diagnosed as terminally ill in the physician's care and the percentage of those patients with cancer. The data obtained did not provide workable estimates of terminal patients in the Helena area.

**Results.**

Direct-care physicians have practiced medicine an average of 13.66 years, and more specifically, have practiced in Helena an average of 7.24 years with a range of 9 months to 20 years. The mean years practiced by indirect-care physicians is 13.5 years generally, and 6.05 years in the Helena area with a range of one year to 11 years. Physicians employed by the Veteran's Administration Hospital have practiced medicine an average of 30.33 years and a mean 13.25 years at Fort Harrison with a range of 2 years to 29 years.
While in Medical School:
Specific Background On
Psychology of Death and Dying

<table>
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<tr>
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</tr>
<tr>
<td>VAH</td>
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Thirteen of the direct-care physicians interviewed felt that they had had specific background on the psychology of death and dying in medical school. Ten felt their background was not specific enough, and one physician did not answer. Sixteen of these physicians have done background work on the psychology of death and dying on their own. Eight have not. Eleven of these have gained background through readings on the subject, and seven have attended training sessions. Additional sources used to gain background on death and dying were college classes, tapes, and religious training.

Of the physicians not dealing directly with the terminally ill, one felt that he had had specific background on the psychology of death and dying through an on-going seminar in medical school. Eight felt their background was not specific enough. Five physicians have done background study on their own; four of those through readings, and one attended a Kubler-Ross lecture while in the navy. Four have not done any background study on their own.

Of the physicians at Fort Harrison, one felt he had had specific background while five felt their background was not specific enough. Four have studied on their own through readings, and two stated that they had not.
Specific Study On
Psychology of Death and Dying

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<th>Physicians</th>
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<th>No Answer</th>
</tr>
</thead>
<tbody>
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</tr>
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<td>Indirect-Care</td>
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<tr>
<td>VAH</td>
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In order to establish what facilities are presently available to terminally-ill patients, each physician was asked what facility or facilities be felt assisted the dying patient. The health-care facilities presently existing in the Helena area are St. Peter's Hospital, Shodair Children's Hospital, West-Mont Community Care, Inc. (a home-health agency), Southwest Mental Health Center, five nursing homes ranging in service for skilled care to rehabilitation of the mentally retarded and mentally ill, and numerous private counseling services. The responses were as follows:

Of the direct-care and indirect-care physicians interviewed, all stated that they utilize the hospitals in the community. Seventeen direct-care and four indirect-care physicians use West-Mont Community Care, Inc. to assist the terminally ill. Two direct- and two indirect-care physicians responded that the Mental Health Center assisted the dying patient. Nine direct- and two indirect-care physicians felt that nursing homes also assist the patient. Four direct- and one indirect-care physicians stated that they would utilize private counselors to help the terminally-ill patient. Two physicians in each of the areas felt that all facilities would assist the patient if needed. Three direct-care and one indirect-care physicians felt that they could assist the patient effectively themselves and no other facilities with the exception of the hospital was necessary. Other assistance possibilities named by either group was the family, ministerial services, and the friends of the patient.
A direct-care physician expressed concern about the role of the nursing home in caring for the dying. He felt that the patient's lifestyle was drastically changed upon entering a nursing home and that this would not be in the best interests of the terminally-ill patient. He felt that the nursing home staff did not understand the many psychological factors of aging and the death process, and that there was "no real feeling" for the dying patient and the family.

In dismissing veterans from the Veteran's Administration Hospital to their respective communities, the staff utilizes many of the facilities available within the community to meet each patient's specific needs. The primary facilities used when a patient returns to the Helena community are West-Mont Community Care, Inc. or placement in one of the five nursing homes available. Many of the other services are provided at Fort Harrison due to its proximity.

To discern the awareness of the hospice concept in this community the physicians were asked if they had heard of the concept and if they had, from what source did they initially learn of it. Of the direct-care physicians, 22 had heard of the concept. Twelve had learned of it from reading, three from associates, three from lectures attended, and two from the organizational efforts of hospice within West-Mont Community Care, Inc.

In interviewing the indirect-care physicians, it was found that seven had heard of hospice. Five had learned of it from reading, and two had learned of it from discussion with associates. Two had not previously heard of hospice.

All of the VA physicians interviewed had previously heard of the hospice care concept. Five had learned of it through readings they have
done, and two from talks with associates.

Heard of the Hospice Concept?

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<th>Physicians</th>
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<th>No Answer</th>
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<tbody>
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<tr>
<td>VAH</td>
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The interviewer then presented a definition of the hospice concept orally to each physician. Possible controversial components of hospice care such as the integral use of the interdisciplinary team and the provision of care regardless of ability to pay were included in the definition read. The interviewee was then asked to respond to the definition emphasizing positive or negative reactions or raising questions. The following responses were noted:

The responses of the direct-care physicians were essentially neutral. The inclusion of an interdisciplinary team was felt by many to be an important part of hospice. The support for families both during and following illness was seen positively. The idea was not to be considered a fad, though, and many physicians felt that they were striving to provide the same kinds of support in their daily practice. One physician remarked on the similarity between the many "Good Samaritan" hospitals across the nation and the concept of hospice care. One physician was suspicious about how the services could be provided at little cost. An extreme opinion was also expressed by one physician: "People do not want to know that they are dying and by using hospice you are telling them."

Indirect-care physicians generally emphasized certain elements of the definition. It was felt that much positive support for the patient and the family was provided by hospice. The team concept was seen as an invaluable element. The inclusion of lay people and professionals other than
physicians in the active decision making on the care of the patient was welcomed by the indirect-care physicians. One physician stated that there was a definite need for education of all professionals and family members of the dying patient on the specifics of hospice care.

The VA physicians were also essentially neutral in responding to the definition. One physician saw a similarity between services to be provided by hospice and those provided in a nursing home. He was concerned with the possibility of hospice gradually becoming like the nursing home, drawing criticisms of quality of care and a general social negativism for the services provided.

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<tr>
<td>Indirect-care</td>
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<td>VAH</td>
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When asked whether they would support the hospice concept if it were to be implemented in this community, the physicians' responses were as follows:

Twenty-two direct-care physicians stated that they would support the concept while two were unsure. One of the latter doubted that Helena was large enough to support a hospice. The cost of such a model of care concerned a majority of the direct-care physicians. At the same time, they felt it is greatly needed and should presently exist. The social effect of such care would promote a healthy attitude toward death.

The physicians who do not deal directly with terminally-ill patients overwhelmingly supported the concept. Nine out of nine interviewed responded with affirmative enthusiasm.
All physicians practicing at the Veteran's Administration Hospital also responded yes. Both indirect-care and VA physicians felt that the dying are alienated by society, family and health-care professionals because of pervasive ignorance in how to care for them, and hospice would serve to dispel the mysteries of the dying process.

The final three questions asked during the interview concerned key elements of the hospice concept: pain control, volunteer and minister involvement in the interdisciplinary team. The Likert response was recorded to each question: that is, strongly agreeing, agreeing, uncertain, disagreeing, and strongly disagreeing.

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<tr>
<td><strong>Element</strong></td>
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<td>Pain Control</td>
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<td>Involvement of:</td>
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<tr>
<td>-Volunteers</td>
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<tr>
<td>-Ministers</td>
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\[ n = 24 \]

Nineteen of the direct-care physicians strongly agreed that control of pain in the final stages of terminal disease should be symptomatic rather than curative. Also important is the fact that the patient be allowed to determine when he needs medication and in what quantity. Three rated their attitude toward pain control as agreeing while two were uncertain. The general feeling could be described as anything a dying patient needs to control his pain should be available to him. One physician remarked that the patient should be made comfortable, but should not be allowed to administer his own medication because of the possibility of overdose would be rather high.
Trained volunteers are members of the hospice interdisciplinary team and are considered professionals in their service to the dying patient and the family. Eleven direct-care physicians rated their attitude toward the volunteer's involvement as strongly agreeing. Five agreed while seven stated that they were uncertain as to how they felt about the use of volunteers. The suspiciousness of volunteers dealt with an individual's motivation in volunteering to work with the dying. If their background was in health-care, they may be worthwhile in caring for the patient; but unless proper training was given and each individual was carefully screened serious problems could result. Proper training was vaguely defined by the physicians. One direct-care physician viewed any volunteer as potentially harmful and disagreed as to their involvement in the hospice team.

Ministers are also considered important professionals in the hospice interdisciplinary team. Sixteen direct-care physicians strongly agreed as to their involvement. Six rated their attitude as agreeing while two were uncertain. All of these responses included a genuine concern for the patient's wishes, and the researcher would add that these physicians would be against the minister's involvement if anything was to be forced on the patient. One physician in direct-care felt that religious support was more important than the physician's support at this point in the patient's life.

### Indirect-Care Physicians

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n = 9
Seven indirect-care physicians rated their attitude toward hospice methods of pain control as strongly agreeing. The remaining two physicians interviewed rated their attitude as agreeing. It was stressed that the medication has to be appropriate to the patient's needs.

On the subject of volunteer involvement five indirect-care physicians strongly agreed and four simply agreed. All stressed the need for volunteers to be properly trained although no specifics for training were offered.

All physicians who do not deal directly with terminally-ill patients rated their attitudes as strongly agreeing with minister involvement in professional hospice care, again, only according to the wishes of the patient.

### Veteran's Administration Physicians

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\[ n = 6 \]

The Veteran's Administration Hospital currently uses the 'Brompton Cocktail' in treating pain in terminally-ill patients. Of the six VA physicians interviewed, two strongly agreed, three agreed, and one was uncertain in rating their attitude toward hospice pain control. The fact that the family can participate in helping administer pain medication was seen positively by these physicians.

Four of the VA physicians interviewed rated their attitude toward hospice volunteer involvement as strongly agreeing while two agreed and one was uncertain. All felt that careful screening was essential, and
that nursing or medical background along with special attitudes were important qualities in a volunteer.

The ratings of attitudes toward involvement of ministers in the dying patient’s care were all positive. Five of the VA physicians stated that they strongly agreed and one stated that he agreed, all specifying the wishes of the patient.

Discussion.

The results of this survey indicate distinguishable elements of awareness and support of the hospice care concept. Nearly all physicians interviewed had previously heard of the concept, many through professional reading. Widespread support of the concept was noted but not without reservations. Most physicians expressing support felt it was a greatly needed addition to the present health-care system but must be approached with caution. Some elements of concern were its economic stability and the threat of governmental regulation to extremes. Only two direct-care physicians were unsure as to whether they would support the concept if it were to be implemented in the Helena area. They felt that they would have to have proof of its effectiveness and additional information before giving their support. It may be noted here that the majority of physicians interviewed had initially learned of hospice and also had done background study on the psychology of death and dying through readings. This would imply that the most efficient way to educate the physicians about any subject is by providing professional reading material to them.

Reactions to the definition of hospice care provided in the interview were largely positive on the aspect of the patient/family unit of care. All the physicians who pointed this out saw the family as needing
support and care as much as the terminally-ill patient. Interestingly, all the indirect-care physicians were in agreement with the utilization of the interdisciplinary team and the value of volunteers in providing care and companionship to the dying patient. Perhaps this agreement is due to their usual role of consultation and ancillary caregiving in the health-care system.

In speaking to the component of pain and symptom control in hospice care, the physicians were in general agreement that whatever the patient needs to manage his pain should be provided without the fear of addiction. The administration of any medication could be given by the family, but some physicians generally felt that the patient should not be allowed to administer it himself because it may lead to suicide in times of despair.

Nearly all physicians interviewed conceded the value and need for ministerial services for the terminally-ill patient but only according to his wishes. It should under no circumstances be pushed upon the patient.

There was much uncertainty and skepticism expressed toward the use of volunteers in caring for the dying. Direct-care physicians felt that the motivations of volunteers did not always coincide with the best interests of the patient. They seem to protect their patients, and they felt that only with proper training and careful screening should volunteers be allowed near the patient. These physicians could not define proper training when asked. A suggestion could be made that physicians should be consulted in the development of a volunteer training program. This would allow them "peace of mind" and at the same time, assure quality of care to the patient. Also, a positive experience with a volunteer on a case may reduce a physician's suspicion. Cicely Saunders recommends consultation beyond the confines of the hospice to gain the respect and cooperation from
the physicians of the patients admitted and to foster a mutually informative exchange (Rizzo, 1978).

No significant number of Likert responses to the three elements of hospice care -- pain control, use of ministers and volunteers -- were in the negative area: i.e., disagreeing or strongly disagreeing. The general impression was of agreement and acceptance or of need to know more before making any decisions. This may be seen as an opportunity for those involved in implementing a hospice program in this community to willingly provide resources to educate the physicians and to work with them in promoting quality care of the dying.

All of the facilities available were not used to their potential capacity. With the exception of the hospitals, West-Mont Community Care, Inc. was used most frequently by physicians. This may be due to the nature of the early stages of terminal illness; the patient is usually ambulatory and able to be at home but does need minimal physical care. At present, only a small percentage of terminally-ill patients remain at home until their death in the community of Helena. Thus, the responsibility of care then returns to the hospital. Nursing homes were also utilized by the physicians but not necessarily to a satisfactory degree. It was felt that with proper staff education and the integration of the hospice concept into daily care, the nursing homes could provide a higher degree of quality care to the terminally ill. Counselors were seen as potential providers of care to the terminally-ill patient and family, but are not presently seen as a necessary component of support by the physicians. It was clear that most of the physicians do now and would utilize any assistance available in the community if they feel it is appropriate for the patient.
One rather enigmatic point to come out of this survey was the confusion and ambiguity surround the medical use of the word "terminal" as in terminal illness. A significant number of the physicians interviewed in any of the three populations questioned the meaning of the word. They pondered the specificity of its use in defining an impending end to a patient's life. In generalities, everyone is terminal; each of us is in the process of dying minute by minute, day by day. When were they, as health-care providers, to specify the length of a person's life based on their technical knowledge? Is it a mere guess or is it based on fact? These questions were taken very seriously by the physicians expressing them. According to Dorland's Medical Dictionary, "terminal pertains to an end." This is a rather vague and meaningless definition when used to describe a disease that has taken over and will eventually consume a person's existence. Out of the discussion of the word came a general discomfort on the part of the researcher at its frequent use in health care language, especially in hospice care, where it is specifically defined in terms of months and used as a program prerequisite.

In all, one latent function of the course of this survey was increased awareness and clarification of the hospice care concept for many of the physicians in the Helena area.

This researcher must admit a limited bias in beginning the interviews. It was felt that the physicians, particularly those providing direct-care for the dying patient, would express more negative attitudes toward hospice care. One variable attributable to the overall positivism expressed may be due to the limited awareness of and experience with hospice. Although physicians have heard of the hospice concept, this does not necessarily mean that their knowledge is sufficient to form strong
attitudes about it. Negative attitudes are usually somewhat researched and supported by facts or experiences and because most of the physicians were not well acquainted with either element of hospice, their attitudes may have been skewed toward the more positive idealistic side.

It is evident from this study that attitudes are a set way of thinking and a combination of one's life-sum experiences. They affect the way we conduct ourselves in our interactions with our peers, our superiors, and those who seek our help. Attitudes are very difficult to discern. On occasion, they can be observed in one's actions or personally expressed if the one being observed or speaking wishes to share his opinions and attitudes. Because the method of this survey was formal interview, it is doubtful that all attitudes relevant to the care of the dying were expressed. A very definite limitation was the type and the subtlety of the questions asked of the physicians. A series of statements presented in matrix form and using scaled ratings may prove helpful in replication to more closely estimate a physician's attitudes.
CHAPTER V

THE COMMUNITY

Helena is part of Montana and part of Montana is Helena. Thus, a few facts about this state are needed to understand and place a community such as Helena.

The state is, to say the least, large and sparsely populated. The combined land areas of Maryland, New Jersey, Michigan, New York, New Hampshire, and Massachusetts just equal the size of Montana. The combined populations of these six states is nearly 70 times as great as the population of Montana (Baucus, 1979).

Health resources available to rural America are appallingly low. There is only one doctor for every 2400 rural Americans compared with one doctor for every 500 urban residents. One hundred thirty-eight counties in the U.S., with a combined population of 5,000,000, have no doctor. This shortage of health manpower aggravates an acute situation with regard to the health of rural residents (Baucus, 1979).

The status of health care in rural states such as Montana is shocking. Differences persist in the health of rural Americans versus urban Americans. Rural areas have disproportionately more older people and poor people. Poor people and older people tend to be sicker than their younger and wealthier counterparts. The health of the rural young is not good either. The infant mortality rate in rural medically underserved areas is up to three times the national norm. Only 20% of
women of childbearing age are rural, but they account for 50% of maternal deaths (Baucus, 1979).

These disparities are also the result of inadequacies of the health-care system, which, in turn, affects the health of every rural resident. The fact that federal government public programs seem to discriminate against rural residents offers proof of the inadequacies. Alarming statistics demonstrate this difference. For example, less than one-third of Medicaid funds go to non-metropolitan areas despite the fact that one-half of the poor live in such areas. Medicare also spends an unequal amount for rural and urban health care. Medicare benefit payments are one-third less for elderly persons in rural areas, compared with metropolitan areas, despite the fact that the percentage of the elderly in non-metropolitan areas is nearly twice as great (Baucus, 1979).

How do these shortages and discriminatory practices relate to hospice care? Hospice provides an alternative to more costly methods of caring for a person diagnosed of terminal illness. It deals with the team concept with many areas of care provided by professionals other than doctors, thus reducing the need for a doctor who does not exist. The patient is primarily cared for by the family in the home, thus reducing the cost and non-availability of hospital services. The philosophy of hospice seeks to provide services to anyone needing them regardless of ability to pay, thus minimizing the financial burden to the patient who is unable to receive adequate Medicare or Medicaid benefits. Though hospice services are somewhat dependent upon government programs, support from the local areas would ideally constitute the financial base of a rural hospice program. Through this grass roots movement, we in Montana can close some of the gaps in health-care resources, particularly in regard to the care of
the terminally ill.

Helena, the county seat of Lewis and Clark County, has a 1978 estimated population of 26,540. The county has a 1978 estimated population of 38,000. Population has increased 15.5% since 1970. Helena is a rapidly expanding community. As the capital of Montana, a majority of the government offices are located here. The median household income in Lewis and Clark County is $14,791, with 10.1% of the population with an income of $25,000 and over and 7.1% with an income of $8,000 - $9,999. Ninety-two percent earn $10,000 or more annually (Chamber of Commerce, 1979).

The median age of the population in Lewis and Clark County is 29.7 years. Twenty-six percent of the population is 50 years and older (Chamber of Commerce, 1979).

The facilities available in Helena that provide health care are: St. Peter's Hospital, Shodair Crippled Children's Hospital, and the Veteran's Administration Hospital, located at Fort Harrison outside the city limits. There are 13.3 hospital beds per 1,000 people in the area (Chamber of Commerce, 1979). In addition, there are six nursing homes, providing a total of 368 beds, and West-Mont Community Care, Inc., a non-profit home health agency serving three counties. Southwest Mental Health Center provides outpatient psychological services to members of the community. Numerous private counselors also practice in Helena.

Sixty-seven physicians, excluding the dentists, have private practices within the city limits of Helena as of May, 1979. Fifteen additional physicians are estimated to have set up practice since that date. Thirteen physicians are currently employed by the Veteran's Administration. There are approximately 2.2 physicians to every 1,000 residents of Lewis and Clark County (Chamber of Commerce, 1979).
Other services available in Helena that may be relevant to the subject of hospice care are the churches and service organizations as well as post-secondary education institutions. There are forty-one Protestant churches and two Catholic churches in Helena. An estimate of membership of these churches is not available. Two hundred and fifty service organizations are listed by the Helena Area Chamber of Commerce (1979). Schools providing post-secondary education are the Vocational-Technical Center, with an enrollment of approximately thirty students in a one-year licensed practical nursing program and Carroll College, a Catholic private college with a total enrollment of approximately 1400 students.

Helena is considered a regional service center, serving a trade area of over 36,000 people and 66% of Lewis and Clark County. Within a radius of 125 miles of Helena, there are more than 65% of the state's population. There are proportionally twice as many professional people employed in Helena as in other urban areas across the nation (Chamber of Commerce, 1979).

Helena also has one daily newspaper, the Independent Record, that reaches 84% of the households in the Helena city zone. The city is also served by four radio stations and one local television station with production facilities (Chamber of Commerce, 1979).

The death rate can be a useful statistic in the establishment of need for hospice care in the community and surrounding area. Three hundred ninety-six deaths occurred in Lewis and Clark County in 1979. One hundred and one were investigated by the county coroner, and 65 of those were determined to be natural deaths occurring at home. Two hundred ninety of the total were not investigated by the coroner and most likely occurred in the hospital, in another institution or at home under a physician's care. These statistics include deaths that have taken place.
at the VA Hospital. The county coroner receives referral for any death occurring in places other than the hospital thought to be of suspicious nature or without a physician's being present or knowledgeable of the person's condition immediately prior to death. The coroner is required by law to sign the death certificate if there is no attending physician. Of a total of 30 deaths occurring in Lewis and Clark County in January of 1980, 19 died in hospitals, five in other institutions, and five at home. The average age at the time of death was 66 years of age for the month of January (Nelson, 1980).

The integration and implementation of the hospice concept in a community setting must take into consideration the components or ideals of hospice care, resources, and sociological factors resent in the community.

Hospice would provide a viable alternative to cost of health care in rural areas as well as to the low availability of hospital beds.

Assessment of various community resources needs to be done in order to most effectively utilize them in the integration of hospice care in Helena. The level of voluntary spirit also needs to be researched as it is a key element in the success of hospice. Financial support from businesses, charitable organizations, and service clubs should also be discerned. Results of the physicians' attitudes survey show favorable support for hospice from these key persons in the health-care delivery system. A follow-up survey of their attitudes and evaluation of hospice care already provided would supply invaluable information to those interested in effective implementation of a hospice program.

Hospice could exist in one of many forms in the Helena community. An autonomous program could function effectively contracting with the
needed medical and nursing services. An autonomous free-standing facility is not feasible at this point in hospice development in a rural community. Definite need would have to be established before the state governmental agencies and the members of the community would advocate a free-standing hospice.

A hospice care unit within the existing hospital would be functional. At the present time, space does not allow the use of a separate area for hospice patients. Hospice patients in need of institutional care are presently cared for in the traditional hospital manner. If a unit were to be established in the hospital, a home care program should also be established to provide continuity for care.

A hospice program functioning within an existing home-health care agency has the benefit of the agency's reputation and client attraction. The hospice program should strive to remain separate in its provision of services other than nursing care to assure quality care to the terminal patient and the family.

All variables of health-care status in rural areas like Helena previously mentioned as well as the many resources available should be carefully considered in the integration and implementation of the hospice care concept in a community setting.
CHAPTER VI

HOSPICE OF HELENA

Hospice of Helena was officially organized as a hospice in December of 1978, as a department within West-Mont Community Care, Inc. Hospice of Helena continues within this framework as of this date.

West-Mont Community Care, Inc. was established in November of 1973, as a non-profit, home-health care agency based in the community of Helena and serving a three-county area: Lewis and Clark, Broadwater, and Jefferson counties. Demography of this tri-county area is sparsely populated: 48,324 people to 6,319 square miles and, thus, predominantly rural. The administrative offices are located in Helena, a city of approximately 25,000.

West-Mont employs 57 salaried and contract personnel and provides service to over 800 patients and families per year.

West-Mont Community Care, Inc. establishes a basis of need for their services because of a shortage of hospital beds and possible long waits for skilled nursing home beds. The day of opening of West-Mont, an acute-care hospital, St. John's, closed, leaving a predicted shortage of beds. Because of this area shortage, home health is relied on as an alternative care service to relieve that shortage. A certificate of need was awarded to West-Mont to provide the following services: skilled nursing, homemaker-home health aid, physical therapy, occupational therapy, speech therapy, respiratory therapy, medical social services and dietician services. An additional certificate of need as required by the Montana
Department of Health and Environmental Sciences is in the process of being filed. Hospice of Helena has also been asked to assist the state government agencies in establishing regulations and standards for future hospice care in Montana.

As an expansion of this agency, hospice also adds to the alternatives for health care in this community and the surrounding area. West-Mont has begun to provide hospice care as a realization of the agency's philosophy first written upon opening. This particular philosophy states, "specialized rehabilitative care and physical and supportive care for the terminally ill will be included as services of the agency."

West-Mont has cared for the dying since 1973 as a part of their usual services but as of December, 1978, it established the department of hospice care to specifically follow the philosophy and organization of the care concept as it is known throughout Britain and the United States.

The relationships between West-Mont and other health-care providers in the area is important in relation to the quality of hospice care to be provided. There are four hospitals and six nursing homes in the three-county area served by West-Mont. One hospital is located in Jefferson County and is a state-run hospital for the developmentally disabled. Two hospitals are located within the city of Helena, one a 140-bed community hospital and the other, a children's hospital providing 50 beds. The fourth hospital is located in Broadwater County and provides 30 beds to the community of Townsend and surrounding area. Four nursing homes are located within the Helena community: one is county-owned and the other three are privately owned. The fifth and sixth nursing homes are also privately owned and are located in Jefferson and Broadwater counties. Contact between the nursing homes listed and West-Mont
is minimal at this time. Visits are made to each nursing home to provide ancillary services to patients, but no evidence is apparent that communication is good at the present time. No formal discussion of possible coordination of in-patient hospice care with the nursing homes or the children's hospital has taken place.

West-Mont's contact with St. Peter's Hospital in Helena is on a daily basis regarding admission and discharge and the making of weekly rounds with head nurses on all floors to provide continuity of care between home and hospital. Formal discussion on the subject of hospice care has taken place between the administrators of the two agencies. St. Peter's Hospital has expressed support of the concept and is interested in incorporating in-patient hospice care in the future. As stated in a grant proposal written by West-Mont describing the St. Peter's/West-Mont relations, "Our relationship with St. Peter's has always been one of excellent coordination and cooperation. We feel confident that even though hospice care has not yet been formally instituted at the hospital, they will do all they can, within the guidelines of physicians' orders, to assure the continuity of the hospice care program for those hospice patients who require hospitalization."

**Hospice Services As Provided.**

West-Mont has provided a number of the health services required in hospice care since its inception. Reportedly, a team concept of care has been followed: "with R.N.'s, therapists, aides, and social workers combining skills and efforts to best serve the patient."

Elements of hospice care that have been heretofore minimally available are currently being strengthened and expanded. These particular
elements are 1) volunteer and 2) bereavement services as well as 3) pain and symptom control.

1) Volunteers

The recruitment of volunteers began in December, 1978, with the first intensive training session taking place in June, 1979. As of this time, three training sessions have taken place, yielding approximately 50 volunteers. Four volunteers are currently working with or have recently worked with a terminally-ill patient, 8 are working with elderly patients, 5 with bereavement groups, and the remaining volunteers are awaiting direct placement and/or are doing such indirect but essential activities as community speaking, fund-raising, publishing the newsletter, developing the library, and performing other clerical duties. Prospective volunteers are initially required to complete an application discerning their skills, experience in working with people, particularly with the dying, and their attitudes toward life and death. They are then required to attend a training session. A typical training session given by West-Mont staff and other professionals from the community covers such topics as communication skills, personal attitude exploration, psychosocial needs of the dying patient and family, psychosocial needs of the aged, the concept components and philosophy of hospice, Hospice of Helena's philosophy and organization, spiritual needs of the dying, bereavement and grief. Continuous inservice training and opportunities for discussion are provided to all volunteers and staff serving West-Mont.

Upon completion of the training, the volunteers are screened by three people on the staff of West-Mont in interview form. The screening process serves to identify the person's motivations in working with the dying and
his emotional stability and to determine what job the person is appropriate for. The screening process allows the person to decide if he or she really wants to work with hospice.

2) Bereavement services

Bereavement services are being extended beyond attendance of the staff and volunteers at the funeral. Hospice care requires complete follow-up support for the family of the patient who has died. West-Mont shall continue contact with the family for three to six months following the death through the visitations of the case manager, social worker, and volunteers. A support group for family members who have experienced a death is available to the general public as well as to West-Mont consumers. The future of such a support group may see further classifications as a teen group, sudden-infant death parents, etc. Psychological services may also be available in the future from the Southwest Mental Health Center. All bereavement care given is fully documented as part of the total patient-family care.

Reportedly, West-Mont plans to offer hospice services to other than the usual hospice candidates. Persons and families experiencing the sudden death of a love one: that is, accidental deaths, emergency room deaths, SIDS deaths, and premature infant deaths, may have need of hospice services in the form of crisis intervention and bereavement support.

3) Pain and symptom control

Pain control provided in the past to patients of West-Mont Community Care, Inc., has not been administered by the patient himself. The family or staff has administered the medication. Now an emphasis is being placed on giving control to the patient and the family on the level they
can handle. Beginning in the spring of 1979, "Brompton's Cocktail" and "Hospice Mix" were added to the methods of pain control available to the terminally-ill patient. These specific oral drugs are prepared by the pharmacy at St. Peter's Hospital.

A new position of Hospice Nurse is now provided at West-Mont. She will coordinate patient care between institutions, coordinate multi-disciplinary team meetings, assist with the training of volunteers and staff, assist in the area of pain and symptom control, and assure that hospice standards are adhered to.

In a grant proposal for Medicaid and Medicare coverage of hospice services, West-Mont states that 269 patients have participated in a hospice program of care in the period 1973 to 1978; 110 of those patients were involved from January to December, 1978. In addition, an average of 27 visits were made to the hospice patients during their period of care. For the past five years the place of death for participants in West-Mont's hospice program is as follows: 48 patients died at home, representing 18% of the 269 patients involved; 159 died at an institution; that is, nursing home or hospital, comprising 59% of the total; and 62 patients died in places other than home or institution, representing 23% of the total hospice patients. The classification of places other than home or institution includes patients for whom a place of death was not obtainable from the medical record.

A 40% increase in patients utilizing hospice services per year is estimated for the next 30 months by the staff of West-Mont. For the year 1979, it was estimated that Hospice of Helena shall provide services to 150 patients, or 12.5 patients per month. The actual number of patients served was approximately 15.
In December, 1979, Hospice of Helena, in cooperation with St. Peter's Hospital, sponsored a three-day symposium entitled "Hospice: A Better Way of Caring for the Dying." Approximately 475 people from throughout the state and Idaho attended. The workshop was funded in part by the Montana Committee for the Humanities. As a result of the interest generated by the large attendance, a coalition for hospice in Montana was created. Hospice of Helena will spearhead the formation of the coalition. Functions of the coalition will be to support and assist in development of hospices throughout the state as well as to clarify the hospice concept and to share expertise in the field. The coalition will also strengthen the impact of hospice on Montana legislation and help to circulate standards in principles of the hospice movement.

Hospice is in its formative stages in every major city in Montana. The form these hospices take ranges from a concerned group of community members to a specialized unit within a hospital to those organized within pre-existing home health agencies.

The future of hospice in Montana is exciting. We shall see new legislation in the future and history in its making!
What we call the beginning is often the end
And to make an end is to make a beginning...

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time...

T. S. Eliot
QUESTIONNAIRE

How many years have you practiced as a Doctor of Medicine?

How many years have you practiced in Helena?

Have you had any specific background on the subject of death and dying in your medical training? (courses, etc.)

   Yes   No

   If yes, how much?

Have you done any background study on death and dying on your own?

   Yes   No

   If yes, in what way?

   ( ) Readings
   ( ) Seminars
   ( ) Other____________________

Approximately how many patients with a diagnosis of terminal illness do you treat within a year's time?

What percentage of these patients have some form of cancer?

Which facilities or services presently existing in this community, do you feel assist a terminally-ill patient?

   ( ) Hospital
   ( ) West-Mont Home Health Care
   ( ) Mental Health Center
   ( ) Private counseling, nursing, etc.
   ( ) Nursing homes
   ( ) Other____________________

Have you heard of the hospice care concept?

   Yes   No

   If yes, from what source?

   ( ) Readings
   ( ) Associates
   ( ) Media
   ( ) Other____________________

DEFINITION OF HOSPICE

Hospice is a medieval term. It denotes a place designed for the provision of comfort and hospitality to travelers along the road. As an alternative way of caring for the terminally ill, it is a program, not necessarily a building, which provides palliative and supportive care for the patient and family. It is under the overall direction of a physician, is possibly nurse-coordinated and employs an interdisciplinary team of ministers, trained and dedicated volunteers, and other persons relevant to each patient's care. The goal of treatment in hospice care is to meet the patient's needs be they physical, emotional, spiritual, social and/or economic. Pain is controlled in a palliative rather than curative way. This care is to be available 24 hours a day, 7 days a week and is provided on the basis of need regardless of ability to pay. Continued support for the bereaved family is also provided.
If this concept were to be implemented in the Helena community, would you support it?

Yes  No  Am not sure

Why?

The hospice concept employs the use of narcotic and non-narcotic analgesics for physical symptom control. The treatment is palliative rather than curative in the sense of improving the quality of life for the patient rather than increasing the length of life. Would you rate your attitude as:

( ) Strongly agreeing
( ) Agreeing
( ) Uncertain
( ) Disagreeing
( ) Strongly disagreeing

...toward hospice pain control

Volunteers are actively involved in the hospice care interdisciplinary team. They are intensively trained and carry their working sum of experience, knowledge, and sensitivity to the family and the patient. They provide support and companionship while performing other specific functions such as transportation, child care, and light nursing care when the family requires time away. Would you rate your attitude as:

( ) Strongly agreeing
( ) Agreeing
( ) Uncertain
( ) Disagreeing
( ) Strongly disagreeing

...toward their involvement

Ministers are also important members of the interdisciplinary team. They participate as equal professionals providing support to the family and patient for spiritual well-being. Would you rate your attitude as:

( ) Strongly agreeing
( ) Agreeing
( ) Uncertain
( ) Disagreeing
( ) Strongly disagreeing

...toward their involvement

Further comments:

Observer's comments:

( ) Direct
( ) Indirect
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