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TO LIVE UNTIL WE DIE

An Overview of Death and Dying
In America since the Eighteenth
Century

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April 19, 1982

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INTRODUCTION

Since man has walked upon this earth he has faced death. It is the final stage of the growth process and is inevitable. It begins the moment man enters this world. Yet, man still has an extremely difficult time accepting and dealing with death. People do not like to think and talk about it and politely change the conversation to a less morbid topic when it is introduced.

In the past attention has been focused on the physical aspects of the dying. The emotional, psychological, and social needs of the terminally ill and their families have been virtually ignored. However, changes in the attitudes towards death and the treatment of the dying are slowly taking root and growing. The total needs of the patient and the family have begun to be focused on in the last two decades.

This paper will trace the attitudes of Americans toward death and dying since the eighteenth century. An understanding of the changes that have taken place is necessary to fully appreciate the efforts being made today to treat the "total" person and the family. It will also report on people and organizations that have helped to change the attitude toward death and the treatment of the dying. A small scale study has been included to appraise the perceived value of those involved in a new program or movement known as the Hospice. The final chapter contains the opinions of the researcher. References and additional suggested readings for background information are included at the end of the paper.

It should be noted initially that as used throughout this paper the term terminally ill refers to patients diagnosed as having incurable illnesses such as cancer and chronic heart disease.

CHAPTER I

Historical Overview of Care for the Terminally Ill and Their Families

Introduction

Most of the literature concerning death and the dying in America begins in the eighteenth century. Since this time four major attitudes toward death and the treatment of the dying can be identified in American society. These four major attitudes took shape in the eighteenth, nineteenth, and twentieth centuries. This chapter provides information on each of these four attitudes and the societal perceptions that contributed to each.

Attitude I

The first of the four attitudes which was reflected by the eighteenth century, might be termed one of "Acceptance". During this time in America death was an accepted part of life. Epidemics, accidents, and acute illnesses (short term illnesses which in the twentieth century can usually be cured, but in the eighteenth century were usually life threatening, e.g., pneumonia) were rampant. The harshness of life (such as severe winter without adequate clothes and food) shortened life spans. Medical knowledge was not yet well enough advanced to be able to cure many of the diseases. As a result many lives were claimed. Hospitals which were few in number and located only in major cities were used for teaching, for care during epidemics, for major surgery, and for care of those who could not afford a private doctor. The private physician was preferred to the use of the hospitals since hospitals were the breeding ground for many diseases, and many people contracted additional illnesses when

admitted to the hospitals. The private physician was also more accessible to most Americans than the hospitals.

The people of this century watched their loved ones die while catering to their every need. The dying were attended to by family and friends, while private physicians did what they could to make the person as comfortable as possible. The dying usually stayed in their own homes surrounded by familiar things and people. As Ariès (1974) noted, death in bed was "a solemn event but also an event as banal as seasonal holidays" (p.59).

Attitude II

The second of the four attitudes which is reflected by the nineteenth century might be termed one of "Dramatization". Instead of being passively accepted as in the eighteenth century, death was romanticized and eulogized in the nineteenth century. Epidemics, diseases, and accidents continued to claim many lives. Due to a slight improvement in living conditions life spans were a bit longer than in the eighteenth century. Medical knowledge was beginning to increase and hospitals, still located mostly in major cities, were growing in number. While the hospitals were still considered as places to die, conditions in them were improving.

A romantic image of the dying and death evolved. The dying were treated as if they were part of a tragic play. Man gave death a new meaning. "He exalted it, dramatized it, and thought of it as disquieting and greedy" (Ariès, 1974, pp.55-6). Mourning, which in the eighteenth century was very private and short-lived, became a public ritual both before and after death. Ariès (1974) suggested

that "this exaggeration of mourning was indeed significant because it signaled an increased difficulty on the part of survivors in accepting the death of another person" (pp.67-8).

During the nineteenth century, the dying assumed a more central, active role in their deaths. The writing of wills became the final way to distribute personal property as they saw fit, with little or no interference from the clergy or the family. The dying made their wishes known concerning what would be placed on their tombstones, what type of funeral service would be held, and what would be put in the church as a remembrance of their lives (Ariès, 1974). There was a strong need on the part of the dying, as well as on the part of the survivors, to have physical reminders of the dead. The dead might be gone, but they were not forgotten.

Attitude III

The third of the four attitudes which was reflected by the first half of the twentieth century might be termed one of "Fear". In comparison to the rate of change in the previous two centuries, attitudes toward death and the dying changed rapidly in the twentieth century.

Ariès (1974) noted:

In our day, in approximately a third of a century, we have witnessed a brutal revolution in traditional ideas and feelings, a revolution so brutal that social observers have not failed to be struck by it. Death, so omnipresent in the past that it was familiar, would be effaced, would disappear. It would become shameful and forbidden (pp.85-6).

Death was rejected and feared, rather than accepted as part of life.

Acute illnesses, such as pneumonia, diphtheria, scarlet fever, and other killers of the eighteenth and nineteenth centuries, were being

eradicated. Medical knowledge was increasing at an astounding rate. Hospitals were now appearing in small cities and towns as well as large cities. Hospitals came to be viewed as places for the sick to be cured rather than as places to die.

The public ritual of mourning, before and after death, and the need to have physical remembrances of the dead continued and amplified. Death was much less accepted as a part of life than in the two previous centuries. Life was to be prolonged for as long as possible. Fighting against death was beginning to be the accepted norm. Society did not believe in giving into the "Grim Reaper".

Attitude IV

The last of the four attitudes which is reflected in the latter half of the twentieth century (1945-1975) might be termed one of "Denial". The fight against death and the "Grim Reaper" was intensified.

The numerous urban and rural hospitals continued to be seen as places for the sick to be cured. Medical knowledge continued to advance at great rates and medical personnel came to be viewed in a reverent light due not only to their ability to cure many ailments, but also to the relative obscurity of medical knowledge available to the layman. Due to technological advances life expectancy became longer, acute illnesses were usually not life threatening (some were even totally eradicated), and cures for newer and more serious illnesses were being found rapidly. The physicians' ability to pronounce a patient cured or terminal became a source of awe to most of society. The medical world became sheathed in a mystical reverence

and doctors became demi-gods to most people.

Despite this status medical personnel were still unable to cure terminal illnesses, such as cancer. They could only prolong the inevitable. As cognizance of the fact that man with all his medical knowledge could not conquer death increased, death became feared and the dying were avoided by most of society. Attention was focused on the prolonging of life by any means. The physical survival of the patient took precedence over the emotional, psychological, and social needs of the terminally ill patients. In many cases the terminally ill were not even told that they were dying. While this might be attributed to attempts to spare the sick person Ariès (1974) suggested:

That this sentiment, whose origin we know (the intolerance of another's death and the confidence shown by the dying person in those about him) very rapidly was covered over by a different sentiment, a new sentiment characteristic of modernity: one must avoid - no longer for the sake of the dying person, but for society's sake, for the sake of those close to the dying person - the disturbance and the overly strong and unbearable emotion caused by the ugliness of dying and by the very presence of death in the midst of a happy life, for it is henceforth given that life is always happy or should always seem to be so (Ariès, 1974, p.87).

Death became almost obscene to all those involved. Along these same lines Veatch commented:

Death, as never before, is looked upon as an evil, and we are mobilizing technology in an all-out war against it. If not death itself, at least certain types of death are beginning to be seen as conquerable. We are being forced to ask the question, "Is death moral in a technological age?" (Wellborn, 1978, p.68).

Ultimately the patients were left alone to die. As Feifel (1977) noted:

When efforts to forestall the dying process fail, professionals usually lose interest and transfer their motivation and resources elsewhere. A hospital's usual perception of operations and appropriate utilization of personnel classifies dying as a relatively ineffective and inefficient enterprise. The unhappy

result is that the dying patient is often left to die emotionally and spiritually alone. We hardly tolerate his farewell. (pp.7-8)

The patient was not the only one who was left alone; the family was also greatly ignored. There was often no one for the family to talk with concerning problems that are associated with terminal illness. The family was not only left alone to face problems while the patient was dying, but also after the death. Pain, isolation, anger, grief, ignorance, and disbelief are terms that describe the attitudes toward death during this time.

Summary

This chapter has summarized the attitudes reflected in the past three centuries toward death and the dying. Attitudes have gone from the banal acceptance of death as a part of life in the eighteenth century to a dramatization of death in the nineteenth century, to fear and denial of death in the twentieth century. However, within the last ten to fifteen years another attitude appears to have been developing. Several individuals seem to be responsible for this development. Their contributions will be discussed in the next chapter.

CHAPTER II

People Who Have Brought About a Change in the Attitudes Toward the Terminally Ill and Their Families

Introduction

Beginning in the mid 1960's a new attitude toward death and the treatment of the dying began to emerge. It was marked by a concern for the patients as a "total" person with social, psychological, and emotional needs. People began to feel that the dying and their families have certain rights and that they should be able to direct the course of their lives. This chapter will discuss the individuals and organizations who are responsible for bringing this change in attitude about.

Kubler-Ross

One of the most well known individuals who has been instrumental in helping to change the attitudes towards death is Dr. Elisabeth Kubler-Ross. Her work with terminally ill people and their families started at the University of Chicago in the 1960's. She conducted over two-hundred interviews with terminally ill patients, their families, and the professionals involved in their care. Based on these interviews Kubler-Ross has conducted many seminars and published many works including her best known On Death and Dying, in an effort to enlighten clergy, medical personnel, social workers, families, and friends about what the dying can teach them if they will only be receptive to the information. As Kubler-Ross stated:

The purpose of my seminars was to teach young students in the helping professions to take a good hard look at their own repressed pains which they often unwillingly projected onto

their patients. My own hope was that more social workers, more clergy, more medical students, and more nurses would have the courage to evaluate their own attitudes toward these patients and toward terminal illness, toward the unresolved losses and pains in their own lives and that they would have the courage to externalize those fears and pains and anguish, freeing themselves from all their negativity and therefore, opening up to the needs and communications of the dying patients, as well as their own needs (pp.20-1).

She has also identified five stages of dying. Knowledge and understanding of which can help those dealing with the terminally ill appreciate the actions and attitudes of the dying. These stages may be described as follows:

The first is one of shock and denial, the "no, not me" stage. This stage is gradually dropped, but may re-occur from time to time. Second, there is a stage of anger - the "why me?" stage. Here is a time when the art of listening is invaluable. Voicing back his feelings or just saying we would be angry also may help the person to pour out his anger and relieve a lot of tension. A third stage described by Kubler-Ross is bargaining. This is a time when the person promises some important thing or behavior as a trade-off for more time, just a little more time. Usually when bargaining stops the person is beginning to face the reality of the closeness of death. Depression is the fourth stage. Close friends may work too hard, to cheer up the dying person who is feeling low. But the individual should be allowed to express his growing depression and grief. By allowing an individual to express his growing depression and grief he can probably reach the final stage of acceptance. This final stage is not one of bitter defeat but usually one of peace within.

These stages can be identified in both the dying person and others who are involved, especially the family. They are not to be considered absolute in the dying process, but can be frequently seen in most terminally ill patients and their families.

Phillipe Ariès

Another person who has brought death and dying out into the open is Phillipe Ariès. A French civil servant turned historian, he provided the first examination of historical attitudes toward death. Ariès

noted a gradual shift in the societal concept of death from simple acceptance to outright rejection of death as a part of society. Ariès has written two books concerning attitudes on death and dying through the ages. These works are not as well known in America as others' works, but they are still very important because they are one of the first documentations of the changing American attitudes towards death throughout the past centuries.

Education

One of the major contributors to the emerging attitudes is education. Education and literature which has appeared since the early 1960's have been very influential in teaching the young people of today about death and the dying. In 1978, "in more than one-thousand educational institutions, from elementary to medical schools, the subject of death was being discussed" (Wellborn, 1978, p. 68). However, there still appears to be a shortage of death education, especially in medical schools. Liston (1975) suggested that emotional resistance to this subject matter has been primarily responsible for this neglect. He further suggested "that increased efforts be made to impart a humanistic approach to terminally ill patients and their families to students during their formative clinical years, not after their individual styles have been fixed" (Liston, p. 193)

Some of the most informative literature has been published by victims of terminal illness or their families. Some of the authors include Stewart Alsop (1973), Cornelius and Kathryn Ryan (1979), and Stephani Cook (1975). Alsop wrote A Stay of Execution after he was diagnosed as having inoperable and lethal cancer. The book details

the fear, the hope, the endless tests, and the eventual coming of terms with his own mortality. It is an account of his life from the beginning to the near end.

Ryan and Ryan wrote A Private Battle after Cornelius Ryan was diagnosed as having prostate cancer. He had kept a meticulous and secret account of his private battle against this killing disease. The account was found by his wife only after his death in 1974. She put the tapes and written accounts together with her own comments about her role in his illness, and published the book five years after her novelist husband died.

Cook was diagnosed as having cancer in 1973 and wrote several articles concerning her fight against the illness. She was still writing two years after her diagnosis. Most of her articles appeared in medical and behavioral science journals.

This type of literature is important because it gives society first hand information about how the terminally ill and their families feel about their illnesses, and how they deal with them. These authors have given society insight into the way they were treated and suggestions on how society could do things differently.

Summary

These people have been very important in helping the fifth attitude develop. People are of the utmost importance in making changes in societal attitudes. These attitude changes have led to many new innovations for the terminally ill and their families, several of which will be discussed in the next chapter.

CHAPTER III

Innovations in Care for the Terminally Ill and Their Families

Introduction

The emerging attitude of care for the "total" terminally ill person has contributed to innovations in their care. Such innovations include self-help groups, more decision making power for the terminally ill, living wills, rational suicide, and refusal of treatment. These innovations have only been available in the last ten years. They will be discussed in this chapter.

Self-Help Groups

One such innovation is the growth of self-help groups. One such group is called Make Today Count. Founded by a cancer victim, this organization is noted for discussions involving groups of cancer patients, discussions involving families of cancer patients, correspondence between the terminally ill in other parts of the country, and telephone hotlines. The objectives of this group and others like it are to allow the patients and their families to talk about their fears, hurts, angers, refusal of treatment, and other emotional and social concerns that are relevant to most terminally ill and their families.

Patient Decision-Making Power

An option that is gradually taking shape is that of allowing the patients more decision-making power than in the past. This includes choosing among available alternative treatments and choosing care facilities that meet their needs. This new found power has

not been assumed without protest from some segments of society. The medical world has been especially tenacious in holding on to the power that most of society has allowed them to have. Patients and their families are beginning to ask questions concerning physical and emotional treatment given by caregivers. No longer is the doctor's word taken as infallible.

Living Wills

A third innovation brought about by the increasing openness in dealing with death allows the terminally ill to choose the manner in which they will die. As Kubler-Ross stated: "This country is a leader in the use of heroic medical efforts to preserve life. (Wellborn, 1978, p.68)

Living wills allow people to decide whether they wish to be put on life sustaining machines or be allowed to die naturally. A typical living will reads in part as follows:

Death is as much a reality as birth, growth, maturity and old age-it is one certainty of life. If the time comes when I, _____, can no longer take part in decisions for my own future, let this statement stand as an expression of my wishes, while I am still of sound mind.

If the situation should arise in which there is no reasonable expectation of my recovery from physical or mental disability, I request that I be allowed to die and not be kept alive by artificial means or "heroic measures." I do not fear death itself as much as the indignities of deterioration, dependence and hopeless pain. I, therefore, ask that medication be mercifully administered to me to alleviate suffering even though this may hasten the moment of death.

This request is made after careful consideration. I hope you who care for me will feel morally bound to follow its mandate (Ambron & Brodzinsky, 1979, pp. 614-15)

Rather than putting patients on life-sustaining machines when there is no hope for them and without these measures would die a natural death, the patients have indicated their desire to die naturally. Although these "right to die" documents are not legally binding in most states,

and their weight and implications vary from state to state, they represent an attempt to meet the needs of the "total" patient.

Rational Suicide

Related to the decision-making power, rational suicide is becoming an option to some victims of terminal illness. Rational suicide may be defined as terminal patients who take their own life before the disease kills them.

An example of the use of rational suicide is found in the case of Mary Jo Roman who committed rational suicide in 1979. Ms. Roman had breast cancer which had not spread to any vital organs and may not have been fatal for sometime, but she felt that rational suicide made possible a truly ideal closing of ones' life span (Shah and Gosnell, 1979,p.87). Ms. Roman spent fifteen months organizing her things, putting together a living memorial in a pine box in her living room, saying goodbye to friends and family, writing her obituary and generally preparing her life to end. She wanted a different death than what is usually afforded to most terminally ill people: dying alone, in hospital beds, inhospital gowns, with tubes going in and out of their bodies, and in great pain. She chose to end her life in her own bed, with a bottle of champagne, a bottle of sleeping pills, wearing her favorite pajamas, and in the arms of her husband.

Refusal of Treatment

While not opting to actively take their own lives, patients may opt to actively not prolong their lives by refusing treatment. Many times cancer is found too late to be successfully treated and the treatment offered is usually physically debilitating and painful.

Rather than suffering the pain and debilitation some terminally ill patients are choosing the option of using supportive care and pain-killing drugs while refusing the option of treatment. Supportive care may include antibiotics to fight infections, vitamins, and other needed medications to keep the body as healthy as possible, but without fighting the killing disease.

Summary

With a new attitude beginning to unfold, new options have opened up for the terminally ill. These are only a beginning to a whole new environment that will allow patients and their families to live the most fulfilled lives possible.

An important option that was not discussed in this chapter is the Hospice movement. This movement, specifically designed for the terminally ill and their families, will be presented in the next chapter.

CHAPTER IV

An Overview of the Development of the Hospice Movement in America

Introduction

One of the innovations in care for the terminally ill and their families is the Hospice movement. In America, this movement is not even two decades old but it holds out many options to the terminally ill and their families. It provides medical and supportive services based on the philosophy of "total" care for the terminally ill and their families. This chapter will trace the history of the Hospice, as well as reporting on the philosophy, the staff, the services, and the types of programs available in the movement.

History

The roots of the Hospice movement in America are based in England. The word Hospice is a medieval term for a Christian way station for travelers, the ill, the poor, and the dying (Foster, F. Wald, and H. Wald, 1978). In the middle ages, Hospices were operated by religious orders for travelers. In the nineteenth century the Irish Sisters of Charity gave the concept new meaning by using the homes for dying patients (Saunders, 1977). This meaning of the concept was reflected in the planning, developing, and implementing of St. Christophers' Hospice. When it opened its doors in 1967 in London, England it also opened a new world for the care of the terminally ill and their families. St. Christophers' Hospice was used as a point of departure for the development of American Hospices.

Dr. Cicely Saunders, founder of St. Christophers, came to America

In the mid-60's to help an interested group of New Haven, Connecticut citizens start a Hospice program much like St. Christophers. This program, like most of the over two-hundred Hospices in America today, puts primary emphasis on home care. Most of the Hospices are concentrated on the east and west coasts, and the number is growing each month. According to the director of North Carolina Hospice Inc., there are thirteen Hospices in North Carolina and twenty-five scheduled to open in the next two years.

Philosophy

The concept of Hospice in America is grounded in four basic principles. These are as follows:

- 1) The patient and family are considered the unit of care.
- 2) Interdisciplinary teams are used to assess the physical, psychological, and spiritual needs of the patient and family to develop an overall plan of care and to provide coordinated care.
- 3) Pain of terminal illness is controlled, but no heroic efforts, such as operations, radiation, and chemotherapy are made to cure the patient.
- 4) Bereavement followup is provided for the family to help them cope with their emotional suffering. (Report No. 79-50)

Vital to the concept of Hospice is the idea that patients know what they want and should be afforded the freedom to not only demand their needs be met but more importantly to have them met. Involvement in care is paramount in the philosophy of the program. This involvement allows the families to still feel a part of the patients' lives, and allows the patients to still feel a part of their families' lives. The patients are given as much control as possible in dealing with their illnesses because the movement believes that the patient knows, above all the experts, what their needs are. Encouragement is given to patients who wish to take care of their personal needs as

much as possible, thus preserving their sense of dignity. Routine practices, rules, and regulations are scuttled for the more important rules of helping the people involved truly live. "There's little doubt that, whether or not sensitive care lengthens a person's days, it does lengthen his life by allowing him to experience it to the very end" (Luciano,1978,p.19). This sentiment is the corner stone for the entire Hospice movement throughout the world.

To help set up uniform care practices the National Hospice Organization has the following standards and criteria for accrediting Hospice programs. These are:

- 1) Palliative care is the most appropriate form of care when cure is no longer possible.
- 2) The goal of palliative care is the prevention of distress from chronic signs and symptoms.
- 3) Admission to a hospice program of care is dependent on patient and family needs and their expressed request for care.
- 4) Hospice care consists of a blending of professional and non-professional services.
- 5) Hospice care considers all aspects of the lives of patients and their families as valid areas of therapeutic concern.
- 6) Hospice care is respectful of all patient and family belief systems, and will employ resources to meet the personal philosophic, moral and religious needs of patients and their families.
- 7) A Hospice care program considers the patient and the family together as the unit of care.
- 8) Hospice care programs seek to identify, coordinate, and supervise persons who can give care to patients who do not have a family member available to take on the responsibility of giving care.
- 9) Hospice care for the family continues into the bereavement period.
- 10) Hospice care is available twenty-four hours a day, seven days a week.
- 11) Hospice care is provided by an interdisciplinary team.
- 12) The optimal control of distressful symptoms is an essential part of a Hospice care program requiring medical, nursing, and other services of the interdisciplinary team.
- 13) The Hospice care team will have a medical director on staff, physicians on staff, and a working relationship with the patient's physician.
- 14) Based on the patient's needs and preferences as determining factors on the setting and location for care, a Hospice program provides in-patient care and care in the home setting. (Leepsom,1980,p.837)

Staff

Today's Hospice programs provide care to the "total" person and

their families. To do this, Hospice programs use paid and volunteer staff members who believe in the rights of the dying and the philosophy of the program. Workers, volunteer and paid, include; nurses, aides, physicians, psychologists, teachers, social workers, lawyers, financial counselors, nutritionists, meal planners, and anyone else who wishes to work with the dying and their families.

Paid and volunteer staff members are trained by the program to help meet the needs of their patients and families. Workers are moved to inactive duty periodically to give them a chance to rest from their emotionally and physically draining work. Workers are assigned to teams when working with their patients. Team efforts are preferred over individual efforts because teams are considered more effective in meeting the patients' and families' needs. These needs are:

- 1) the patients' and the families emotional state and the ability of each person to cope with problems and emotional stress, 2) the patients' physical needs, 3) the families financial needs, and
- 4) spiritual needs and religious preferences of the patients and families. (Report No. 79-50)

These are constantly reevaluated and appropriate action taken.

Services

Services are based upon an assessment of the needs of the patients and their families, with the following factors being taken into consideration: pain medication, physical maintenance, and emotional and psychological care for patients and families are provided through a team of workers. These teams provide this care for patients and families in their homes or in medical facilities.

Pain medication is an important part of allowing patients to live by allowing the patient to be as pain free as possible. Their

illnesses usually involve severe pain, that until several years ago could only be controlled through strong drugs that kept the patient almost totally unaware of their surroundings. Now with a new awareness of the need for drugs that kill the pain, but allow the patients to live as normally as possible, such combinations of drugs like Bromptons' cocktail have been developed. This mixture, which was developed for use by the English Hospices and brought over to America, consists of analgesics, codeine, morphine, and other drugs that alleviate the pain of terminal illness while allowing functional living. The English mixture contains heroin which is illegal in this country. There has been a push by leaders of the Hospices as well as the terminally ill and their families to allow the use of certain illegal drugs for the terminally ill. Marijuana has just been legalized for use by cancer patients to alleviate some of the side effects of treatment, such as radiation and chemotherapy. Proponents of legalizing such drugs as marijuana and heroin might agree with Dr. Eric Wilson, Medical Director of St. Lukes' Hospice in England, who stated: "I have been disgusted seeing people who are going to be dead within a few hours or days being hooked up to all this blasphemous plumbing when all they really need is a friendly word, a nice cup of coffee and some heroin". (Satchell, 1977,p.23)

Physical maintenance includes the use of antibiotics, vitamins, and proper nutrition to keep the person as "healthy" as possible. Emotional and psychological care is given by trained professionals as well as lay volunteers to both the patients and families. The range of services includes in-depth counseling provided by trained profes-

sionals, as well as companionship provided by lay volunteers.

Supportive services are also provided by the Hospice workers or by community organizations to which referrals are made. These services include: caring for pets, hair grooming, day care for patients, respite* care for families, grocery shopping, meal preparation, and house cleaning. These services are offered to assure that the physical, emotional, and social needs, including the need for self-esteem are met. The following table summarizes the services provided by the fifty-nine Hospices operating in the United States in 1978:

<u>Services</u>	<u>Percent of Hospices that</u>		
	<u>Provide service</u>	<u>Coordinate or make referrals***</u>	<u>Do not provide, refer, or coordinate service</u>
Medical services:			
Home health, skilled nursing care, and aide	68	20	12
Home visits by physicians	41	30	29
Psychiatric consultation	46	24	30
Pain control: Medication, Surgery,**	63	22	15
Radiation,**	7	59	34
Physical therapy	7	66	27
Occupational therapy	41	39	20
Inpatient care	29	32	39
Outpatient care	30	36	34
Ambulatory services in an outpatient facility	19	30	51
Supportive services:			
Bereavement followup	93	2	5
Day care for patient	10	7	83
Homemaker services	30	48	22
Meal prep. at home	17	59	24
Respite care *	63	5	32
Death education	61	3	36

***Seventeen percent of the Hospices do not make referrals to other agencies.

** These services are rarely performed since they are normally not medically necessary to relieve terminally ill patients' pain.

* The patient receives total care from Hospice workers in a facility

* or in the home so that family members or primary caregivers in the home may have a couple of days or more of rest from the stress of caring for the patient. (Report No. 79-50)

Five types of Hospices

Even though the staff and services are geared to the same goals, there are five types of Hospice programs available in the United States. These are: 1) A free standing system, 2) A home health agency, 3) A palliative care unit, 4) A Hospice program within a hospital, and 5) Shanti Nilaya.

A free standing system consists of a facility that is not attached to any other medical facility. Care is centered around patients in the facility, but care is also provided for patients who are at home. Patients are able to move from their homes to the facility as levels of care vary.

The second type of facility is the most common in the United States. Services are provided primarily in the homes. Supportive care is available for patients during hospital or nursing home stays.

Palliative (defined as alleviating or lessening pain without curing) care units are located in existing hospitals. These units are attached to the hospital, but are used totally for Hospice patients. Care is provided in the unit, in the hospital, and in the community by the Hospice workers.

The fourth type of Hospice has taken beds within the hospital. Terminal patients are given supportive care while in the hospital, and care is given when the patients are at home. These units may be single beds in various parts of the hospital, or may be a ward type arrangement.

Shanti Nilaya is a teaching center for Hospice workers in which patients may also reside. There is only one of its kind in the United States, and it was developed by Dr. Kubler-Ross. Caregivers learn how to deal with the problems they face while dealing with the problems of the patients and families. Special programs are offered to caregivers, patients, and families. As Foster noted, "It is' dedicated to the promotion of psychological, physical, and spiritual health and is a retreat for growth and healing and the development of human potential'" (Foster, et.al. 1978, p.24).

Summary

The Hospice movement is one of the most recent innovations in care for the terminally ill and their families in the United States. Although individual Hospice programs may vary in terms of structure and services, they are all based upon a single philosophy of "total" patient care, taking into consideration both the needs of the patients and of their families. A small scale study of a local Hospice will be presented in the next chapter.

CHAPTER V

A Study of a Local Hospice

Introduction

As noted in the previous chapter, the Hospice program is relatively new in the United States. While it appears to be based on the sound philosophy of "total" care for the patients and families involved with terminal illness, there has been little actual research done concerning the attitudes of the caregivers and the patients involved in the programs. Feedback from the people involved in the programs is important in deciding if the program is effectively meeting its objectives.

The purpose of this study was to gather some of this information on a local level. Specifically it sought to: 1) determine the attitudes of the patients towards the program, 2) determine the attitudes of the caregivers (social workers, nurses, lay volunteers, and aides) toward the program, and 3) compare the attitudes of the patients and caregivers on selected aspects of the program.

Background Information on a Local Hospice Program

Prior to actually conducting this study a questionnaire (see Appendix A) designed to obtain background information on the program was completed by the program's administrator. This questionnaire was concerned with what type of care was available before the Hospice program was put into action, who or what brought the Hospice program into being, what type of services are available at the present time, what improvements were envisioned for the future, and what rationale

is behind these improvements.

The geographic area involved had various services available before the inception of the Hospice program, but they were very fragmented. These services included physicians, hospitals, nursing homes, clergy, home health services, social services, and other community services. A local physician, aware of the need for coordinated medical and supportive care for the terminally ill patients and their families, spearheaded the Hospice program. He assembled a group of interested persons to discuss the Hospice concept of care. This group then proceeded with planning for a Hospice organization. This program has been available to area residents for over two years.

Services for the terminally ill are not only available through the Hospice program but also by referrals to community organizations and private sectors. This local program is a home health organization. Services include; In-home care, care during hospital and nursing home stays, the availability of psychologists, lawyers, financial counselors, nutritionists, social workers, nurses, and nurses' aides, and emotional and social support by volunteers and staff. The patients retain their private physicians throughout their illness.

The administrator of this program would like to see the following continuations or improvements: 1) continued interaction with physicians, agencies, hospital and nursing homes, 2) continued education for staff, 3) more emphasis on bereavement care, and 4) continuous public and professional education. This would hopefully lead to an improved team approach, improved continuity of care, improved knowledge and

skills, upgrading of bereavement support, upgrading of skills in dealing with death and dying for various professional groups, and increased community awareness.

The administrator of this program is very pleased with its progress. She envisions improved services as the program matures. In February this program had approximately forty patients in its care and over one-hundred staff and volunteers.

Subjects

Thirty patients and fifty-one caregivers associated with a local Hospice program operating in southeastern North Carolina served as subjects in this study. Of the eighty-one subjects asked to complete a questionnaire, eleven of the patients (37%) and thirty-eight of the caregivers (72%) did so. Background data regarding sex, age, marital status, education, and length of time in the program is summarized in Tables 1 and 2.

TABLE 1

Background Statistics on Patients

Sex--Male-4 Female-7
 Age \bar{X} =66.5 years
 Marital status--Single-1, Married-5, Widowed-3,
 Sep/Div.-2.
 Education \bar{X} = 11.9 years
 Length of time in the program \bar{X} = 8.8 months

TABLE 2

Background Statistics on Caregivers

Sex--Male-4 Female-33
 Age \bar{X} = 44.4 years
 Education \bar{X} = 16 years
 Length of time working in the program \bar{X} = 13 months

Procedures

Initially two area Hospices were contacted and asked to participate in a study. Administrators of both programs agreed to take part but due to time factors only one was able to actually participate. Two questionnaires (see Appendixes B and C) were developed to illicit the attitudes of the patients and caregivers involved towards the care and the treatment provided.

The questionnaires were submitted to a panel of graduate students to juror. Their comments and suggestions were considered and when appropriate, incorporated. The questionnaires were then sent to the director of the local Hospice program that would participate in the study so that she could make suggestions. The final copies were then prepared. Eighty-one copies were sent to the director for distribution, thus guaranting confidentiality. Forty-nine were completed and returned.

The responses to the patients' and caregivers' questionnaires were tabulated and analyzed by means of the Chi square (χ^2) technique. Conclusions were then drawn.

Results

Results of the Chi square analysis for the patients indicated they significantly ($p < .01$) agreed with these statements:

- A) My physician answers my questions truthfully and openly.
- B) Hospice workers answer my questions truthfully and openly.
- C) My hospital stays were made comfortable by very caring staff.
- D) My physical discomfort is of primary concern to the Hospice workers.

- E) There is always someone on staff in the Hospice program to talk with when I feel the need.
- F) I receive nurturing in the Hospice program.
- G) I feel that the Hospice program has been very helpful to me during my illness.
- H) My family feels very comfortable in the atmosphere of the Hospice program.
- I) I feel less of a burden to my family since entering the Hospice program.
- J) My personal dignity is respected in the Hospice program.
- K) I feel very comfortable in the Hospice program.

The patients significantly ($p < .01$) disagreed with these statements:

- A) My wishes for privacy are not respected in the Hospice program.
 - B) Family members are given more consideration than I am in the Hospice program.
 - C) I wish that everyone would just leave me alone.
 - D) Hospice workers are not available to my family and me when we need them.
 - E) Little concern was shown for personal problems outside the scope of my illness, (i.e. financial situations, transportation, etc.) before entering the Hospice program.
 - F) Little concern is shown for personal problems outside the scope of my illness, (i.e. financial situations, transportation, etc.) since entering the Hospice program.*
 - G) I feel that the Hospice staff and my doctor evade discussing my medical condition(s) with my family and me.
 - H) Hospice workers are very uncomfortable around me.
 - I) There is very little emotional support given to my family and me in the Hospice program.
 - J) There was very little emotional support given to my family and me during my hospital stay(s).
- * ($p < .05$) in this case only.

Their responses to the following questions were what would be expected by chance alone:

- A) I feel that I get more personalized care now that I am in the Hospice program than when I was in the hospital.
- B) Companionship is not top priority in the Hospice program.
- C) My wishes are considered over that of my family's.

Results of the Chi square analysis indicated that the caregivers significantly ($p < .01$) agreed with these statements:

- A) Patients receive nurturing of their needs.
- B) I feel the Hospice program is meant to help the dying and their families in every way possible.
- C) There is always someone available for the patients and their families to talk with.
- D) Patients wishes for privacy are respected.
- E) When patients ask about their illness they are given straight-forward answers.
- F) The patient's physical comfort is of primary importance.
- G) Patient's wishes are considered over that of their family members.
- H) I feel that working with the terminally ill is a very rewarding and satisfying job.

The care givers significantly ($p < .01$) disagreed with these statements:

- A) Patients are dying and therefore don't need much attention.
- B) Patients expect too much personal attention for their non-medical needs.
- C) I find the situation to be very depressing because the patients are so close to death.
- D) Companionship is not considered a top priority in care giving.
- E) Personal dignity is not considered in the care of the patients.
- F) Family members intrude on the relationships between the patients and the caregivers.

The responses of the caregivers to the statement that "Family Members direct what type of information is given to the patients" were what would be expected based on chance alone.

Comparison of the attitudes of the patients and caregivers indicated no significant differences on any of the points compared. These points were:

- A) Patients receive nurturing of their basic needs.
- B) Patients questions were answered truthfully and openly.

- C) People were available for the patients and their families to talk with.
- D) Patients' wishes were considered over the patients' families' wishes.
- E) Physical comfort of the patient was considered important.
- F) The patients' personal dignity was maintained.
- G) A comfortable, open atmosphere was present within the Hospice program.

Discussion

While this study is too small to be able to make generalizations toward the entire Hospice movement, the results do suggest that in at least one of the over two-hundred Hospice programs nationwide, the patients and caregivers feel good about the care provided and perceive this care in the same manner.

The respondents indicated a positive attitude toward the entire program. Patients indicated that the Hospice program was very beneficial to them and their families. They indicated that they felt comfortable in the atmosphere of the program and their personal dignity was maintained. They indicated that Hospice workers were supportive of their families and of themselves.

Caregivers indicated that they were supportive of the families and the patients, and they seemed to enjoy their work. They believed in being open with patients and families and they were supportive of the program. Overall, the attitudes reflected by this study are in line with the philosophy of the United States Hospice movement. This program believes in "total" care for the patients and families involved.

More extensive research on larger samples as well as more geographically diverse samples are needed before definite conclusions regarding the effectiveness of the Hospice programs may be drawn. These

studies would be very beneficial in showing the need for the program as well as in keeping a check on problems that can easily occur in any new movement. However, the willingness to participate evidenced by the administration of the local Hospice and the individuals involved is most encouraging and would suggest that such large scale studies are indeed possible.

The author's conclusions and opinions will be presented in the next chapter.

CHAPTER VI

Author's Conclusions and Opinions

This paper has traced the attitudes held by most of society toward death and the dying from the eighteenth century to the present, as well as the development of various types of care for terminally ill persons and their families.

The fear of death held by western society led to the dying being shut away in to hospital wards or nursing homes. Their families were left to cope with the illness and loss without much support. Patients had very few rights concerning their illnesses and the treatments involved. No one wanted to discuss death. When a terminal patient wished to discuss his death, or some aspect of his illness he was shut off with placating phrases, such as; "Don't talk like that", or "You're not going to die". Most of society did not realize that this left the person as isolated as if he were already dead and buried.

Fortunately many of the destructive attitudes of the past are changing. Acceptance of death will never be complete, but we can learn to accept the dying, and accept them as viable human beings. The dying have so much to offer society, if we would only listen. Care and support are needed to help terminally ill persons and their families cope with this final stage of life.

My interest in this topic is based upon both personal and professional concerns related to care of the terminally ill and their families. In February of 1981, my father died of cancer, seven months after receiving this diagnosis. There was very little support offered by any of the medical facilities or personnel that were involved. Their

only concern was for the physical side of my father's illness. I became acutely aware of the need for a variety of "total" care options for the terminally ill and their families. As a social work major, I recognize that part of our professional responsibility involves developing responses to a wide range of human needs. In the areas of services to terminally ill persons and their families, the Hospice movement appears to be filling a void that has existed for many years. This movement cannot and should not carry the entire burden of care for this most neglected minority. People and organizations must help to carry the entire movement of "total" care for the terminally ill and their families in the right direction.

This new direction in care needs to be nurtured ever so carefully, watched over, and guarded by society so that it does not stray from its original destination. That destination is to allow people to live, truly live, until they die.

Appendix A
ADMINISTRATIVE QUESTIONNAIRE

1. What type of care was available to the chronically ill and their families before the Hospice program was put into action?

2. Who or what brought your Hospice program into being?

3. What are the exact services available to the patients and their families? Please check all blanks that are applicable.

In-home care _____

In-residence care _____

Psychologists _____

Physicians _____

Specialists _____ (please specify) _____

Social Workers _____

Nurses _____

Nurses aides _____

Other (please specify) _____

4. What changes and/or improvements, if any, do you envision in the future?

5. What is the rationale behind these changes and/or improvements?

Additional comments you care to make:

Appendix B

PATIENT'S QUESTIONNAIRE

DIRECTIONS: Please provide the requested patient background information on the lines below.

Age _____

Sex _____

Last grade in school completed _____

Marital status: Single _____

Married _____

Widowed _____

Sep./Div. _____

Last job held _____

How long have you been in the Hospice program? _____

When were you diagnosed as being chronically ill? _____

What medical services did you receive before entering the Hospice program?

Please check all blanks that apply.

Hospitalization _____

Out-Patient _____

Private Physician _____

Other (please specify) _____

Person who completed questionnaire _____

DIRECTIONS: Please read each of the following statements and decide whether you Agree with(A), are Undecided about(U), or Disagree with(D) each one. Indicate your opinion by marking the appropriate box.

1. My physician answers my questions truthfully and openly.
2. Hospice workers answer my questions truthfully and openly.
3. I feel that I get more personalized care now that I am in the Hospice program than when I was in the hospital.

	A	U	D

- 22. Hospice workers seem very uncomfortable around me.
- 23. My personal dignity is respected in the Hospice program.
- 24. I feel very comfortable in the Hospice program.

A	U	D

Appendix C
HOSPICE WORKER'S QUESTIONNAIRE

DIRECTIONS: Please provide the requested background information on the lines below.

Age _____

Sex _____

Position _____

How long have you worked for the Hospice program? _____

Educational background _____

DIRECTIONS: Please read each of the following statements and decide whether you Agree with(A), are Undecided about(U), or Disagree with(D) each one. Indicate your opinion by marking the appropriate box.

	A	U	D
1. Patients receive nurturing of their needs.			
2. I feel the Hospice program is meant to help the dying and their families in every way possible.			
3. There is always someone available for the patients and their families to talk with.			
4. Patients are dying and therefore don't need much attention.			
5. Patients expect too much personal attention for their nonmedical needs.			
6. Patients' wishes for privacy are respected.			
7. When patients ask about their illness they are given straight-forward answers.			
8. I find the situation to be very depressing because the patients are so close to death.			
9. Companionship is not considered a top priority in care giving.			
10. The patients' physical comfort is of primary importance.			

- 11. Personal dignity is not considered in the care of the patients.
- 12. Patients' wishes are considered over that of their family members.
- 13. Family members intrude on the relationships between the patients and the care givers.
- 14. Family members direct what type of information is given out to the patients.
- 15. I feel that working with the terminally ill is a very rewarding and satisfying job.

	A	U	D

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Suggested Readings

This list of suggested reading includes a number of useful books that were not cited in the text, as well as some previously mentioned.

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