

# ***The Hospice Concept in Health Care***

## ***Kathleen Ann Allen***

The hospice movement has been receiving a great deal of attention lately. Care of the dying has become the byline for any professional as well as non-professional writers. You are sure to find at least one article in any current journal for health professionals devoted to the care of the terminally ill. Television has presented news miniseries and specials on the needs of the dying, and syndicated columnists, such as Sylvia Porter, have written on the subject. Why all this interest in the dying? Why all this interest by the health professionals who have been dealing with dying clients for centuries? One answer has been to attribute this recent attention to the fact that people are now living longer than even a half-century ago. However, the answer is quite likely much more complex than that. There is currently an internal evaluation process being carried out in most health related facilities. These evaluation procedures have evolved from government and consumer demands over recent years. It has become a recognized fact that within the medical and nursing professions not enough attention has been given to the care of the dying and/or the handling of the dying client. Attempts are made to correct this dilemma. Medical and nursing schools are now offering courses and recommending them to their students on such topics as "Perspectives on Death and Dying." They have not reached a required status in most college curricula; however, death and dying is at least accepted as a topic to be discussed in the professional preparation of the future health care practitioners in this country.

When considering the health care needs of the dying today, many think of the work of Dr. Elisabeth Kubler-Ross with her theory of the Stages of Death and Dying, and the work of other thanatologists, and most recently the hospice movement. This work will focus on hospice. Just what is the Hospice concept and what are its roots?

The term "Hospice" comes from the Latin root *Hospes* which means both host and guest. It implies, therefore, a mutual caring between practitioner and recipient. The first Hospice in modern times is the well-known St. Christopher's in London from which the American Hospice movement grew. However, the original hospices date back to medieval times. They were way stations established by religious communities to provide care and personal attention to those who became sick or wounded on their travels to the Holy Land. They became famous for the excellence and compassion of the care given in them. They were the historical institutions from which more specialized modern institutions such as hotels and hospitals have evolved. Thus, Hospices have come to be remembered as a community for sojourners along the way, a place of replenishment, refreshment, and care. The reigning moral theme at the time of the medieval hospices was "as long as you do it for the least of my brothers that you do unto me." Whatever the moral tone of our contemporary society, the Hospice movement seems to be catching on. We will have to face the inevitable one day -- our own death. We can deny it, cry about it, worry about it, laugh it off, or we can be prepared for it. Realizing that no one has found a "way out" throughout the centuries, many today are trying to insure that they will

die with dignity and with others around who genuinely care for them. That is what Hospice workers have been trying to accomplish.

For anyone who has ever had a loved one die in the cold, sterile atmosphere of a hospital, it isn't easy or necessarily dignified. It is not entirely the fault of the medical and nursing staff either. I believe that I can say that as a nurse who has been in life and death situations throughout my career. Knowing someone is going to die and knowing all that you have been trained to do is useless in terms of prolonging that person's life, is not only the most frustrating and helpless feeling, but also one of the saddest that a nurse has to face. Nurses must deal with those feelings early in their careers to be of any benefit to the dying clients entrusted to their care.

Today, Hospice can be equated to a special way of caring for those incurably ill, and its goal is to blend the best of professional care with the most personal service possible so as to meet ongoing client needs for comfort and relief even when a cure is no longer possible. Hospice was developed to supplement, not replace, existing medical facilities or services. The staffing of the Hospices is primarily volunteers who are carefully selected and trained, and made up of both professionals and non-professionals.

The purposes of the Hospice approach, an interdisciplinary total care approach to the care of the dying, are as follows: to establish a community of caring for clients diagnosed as having an incurable chronic illness with a life expectancy of six months or less and for their families; to help ease the physical and psychological discomforts inherent in such illness and death; and to assist families during the bereavement period which includes follow-up care after the death of the loved one. The Hospice approach is family oriented, with the family as the unit of care. It is a highly people-oriented approach also, i.e., an interaction and caring between humans. Hospice is not a place, but a concept or program of health care. The Hospice approach is dedicated to removing the stigma of death and isolation that accompanies the institutionalized way of dying. Dr. Leigner, a specialist in radiation therapy at St. Luke's Hospital, N.Y.C., states hospice "teaches the realization and acceptance (consciously of dying and death as part of being born and part of the struggle of life."

The hospice goals vary within each institutional setting. The general or overall goals would include the following: to help the client live as fully as possible, conscious and free of pain, and in control; to support the family as the unit of care; to keep the client at home as long as appropriate; to educate health professionals as well as lay people, to supplement, not duplicate, existing services; and to keep costs down. The concept of remaining home is the "ideal" Hospice approach.

Dr. Cicely Saunders made the Hospice synonymous with more humane care of the dying and good medical practice. In 1967, Dr. Saunders founded St. Christopher's Hospice in London, England. It is indeed a way station for the dying - a place where people can go in the final stages of degenerative diseases. It is a place of warmth and support. St. Christopher's has a charitable foundation; it is

funded by friends and families. A client, however, is never turned away because of financial inadequacy.

Dr. Sylvia Lack began the United States hospice Movement after working at St. Christopher's and St. Joseph's in London. The design of the New Haven Hospice accommodates the primitive fear of and revulsion for the dead body. This hospice is the first here in the United States to be closely modeled after St. Christopher's. The Federal government's attitude toward the birth of the Hospice movement in the United States has been one that is cautious and investigatory by nature, but finally approving. There are at this time 300 operating Hospices in the United States, with more than 125 planned.

In the United States, death has finally come out of the closet. In the past, we did not know when to let go. Our society, including trained physicians, denied death. We still have a need to keep clients "biologically alive" with modern technology. Medical and nursing staffs haven't looked at dying clients realistically. All they saw in the death and dying around them was failure and the terror of their own inescapable death -- their mortality. The only health care deemed acceptable was successful care -- care that saved a life.

The group best suited and motivated to take the lead in the provision of care and comfort for the dying seems to have been religious communities or religious lay groups. An example of an earlier undetected "Hospice" in the United States is Calvary Hospital in the Bronx. It was founded in 1899 by Mrs. Annie Storrs and a group of Irish Catholic laid women for the care of the destitute, dying of cancer. It is now owned by the New York Archdiocese, and it is the only hospital in New York State exclusively for the terminally ill. This recently modernized hospital can house up to 200 clients. It is a voluntary, non-profit facility. Although a pioneer in the care of the dying, it still remains a Hospice experience within a hospital setting. Philosophically little has changed in 82 years at Calvary. V. Dunigan, 5 C.M. referred to Calvary Hospital in the May, 1980 Catholic Digest as a place "where the dies come.

None of the New York area Hospice programs at present fulfill the "ideal." The Hospice program that is closest to the "ideal" is the one in Riverside, New Jersey. It was set up in January of 1977. It is a program of medical, spiritual, and social support services established to enable terminally ill cancer clients to die at home. Its philosophy is to provide humane, compassionate, palliative medical and social care to clients with cancer and their families. Its primary goals are to provide support necessary to help the client die with dignity and minimize the destructive impact of the cancer death on the surviving family members. The Riverside Hospice has a back-up in-patient unit with the home care program receiving the primary emphasis. This particular hospice is funded through the National Cancer Institute. The dying clients and their families meet with the hospice team initially to identify the problems, set goals, and make any necessary referrals, and then meet as often as necessary.

There are a variety of programs markedly diversified that have been labeled as Hospices. The American Hospice Movement recognizes several variations from the "ideal" home-based set-up. St. Luke's in New York City was organized in 1975; it was the first hospice program incorporated into a United States medical center, and it was the second hospice established in this country (New Haven being the first). It is open only to adults; it has an in-patient and an outpatient approach. Influenced by Dr. Saunders, pain management with medications is geared toward maintaining an alert and rational client for as long as possible. This is a voluntary, non-profit hospital. The goal of this integrated, consultative Hospice team within the hospital medical center is to improve the quality of life that remains for their clients.

Twenty-six Hospice programs had been selected initially by the Health Care Financing Administration of HEW as two year *demonstration* projects for reimbursement through Medicaid and Medicare. One of the fifteen in New York State participating; in this project has been the Brooklyn Hospice, sponsored by the Metropolitan Jewish Geriatric Center. It is a 50 bed in-patient facility with out-patient services too. Its goal is to foster the spiritual, emotional, and physical well-being of dying clients and their families.

North Shore Hospital in Manhasset in Nassau County has an H.O.M.E. (Home Oncology Medical Extension) approach for advanced cancer clients wanting to be treated at home. They have a mobile van equipped with lab and medical supplies. Their outreach program offers chemotherapy. This program was one of the pioneers in alternatives to hospitalization for dying clients.

Another Hospice program is St. Rose's free home for incurable cancer run by the Hawthorne Dominicans which was built in 1912. It houses 60 clients. There are no lab or work-up facilities on the premises. Their goal at St. Rose's is to keep the client pain-free and alert. Pain medications when needed are given before the patient has to request them as it is done in St. Christopher's. This facility will accept anyone who is unable to pay for care anywhere else. St. Rose's was founded by Rose Hawthorne, daughter of Nathaniel. It relies on the donations of the sympathetic public. It is one of many homes run by these Sisters in this country.

Mercy Hospital Hospice in Rockville Center in Suffolk County is family centered with volunteers an integral part of the program. It is part of the general hospital setting, i.e., a unit with its own staff.

The first Hospice in the world planned for children is St. Mary's Hospice in Bayside, Queens. It emphasizes the concept, more than the institution. St. Mary's program will have ten beds, and 60-70 out-patient department clients. There will be active in-service education programs. There will be a cost of \$125/day. However, at the outset it will be a funded project; therefore, there will be no charge to clients. There will be continuous outcome, process, and structure evaluations done in the program. The approach taken with the children will be one characterized by honesty.

Thus, one can see the "variations on the theme" concept applied to the set-up of a few Hospice programs in the New York City vicinity. The main similarity is a caring community of people trained in their various skills and offering a service and fellowship, not only to the client, but to the entire family unit. There are no prejudices in the Hospice Movement as to race, creed, or financial abilities. Since all of us will one day die, all of us are entitled to the same care and concern from our fellows. This caring community operates on its own principles, autonomous in terms of its professional procedure (Stoddard, 1980). The major difference perhaps from this way of caring for the dying from the well-known hospital approach is that the Hospice is planned as a therapeutic environment designed from the client's point of view. What makes Hospice a better way of dying and a "good death" is the insistence upon fitting care to the client, rather than forcing the client into the relentless routine of some institutions, that are basically designed and run for other purposes. "The Hospice provides individuals with the process of pure being, as it is acted out in giving and receiving of human love" (Stoddard). This is the key to the Hospice movement and the Hospice success.

There has long been a need to talk about death and dying and that need continues even today, but we also need to begin to take action on those things that will enable us to improve the care of the terminally ill. Death need not, nor should it, be experienced alone.

The future of Hospice is bound up in the growing awareness that this is a better and more humane attitude than that which has preceded it.

Hospice has developed much recognition these days, so much so that there is a National Hospice Organization in McLean, Virginia, 22101. There is also a Hospice Institute for education, training, and research, in New Haven, Connecticut, 06511. Hospice Inc. in Connecticut is a non-profit corporation with voluntary members. The institute has been able to estimate the cost of the hospice care to be \$450 over a 3 month period for home care, which is far cheaper than hospital care.

Nurses are interested in the people-oriented type of care in the Hospice setting, which attracts capable, caring nurses. The nurse's role in the Hospice is as diversified as it is in other nursing settings. The nurse is responsible for pain and symptom management, teaches the family basic nursing care, lends emotional support to client and family through close of life and through bereavement, and makes home visits. The nurse, in this type of care, needs to listen, touch, and hear, be thoughtful and competent, open and willing, use silence and be honest. Since Hospice is a way of life - a commitment--those attracted to this special caring usually have some commitment to spiritual values, and are outgoing individuals who enjoy helping and caring for others. As in most nursing services, hospice clients require 24 hour a day, 7 days a week coverage. The nurse needs to be accessible to the client, and have a kind of candor and conscience in filling the information gap.

As for physicians, Dr. Twycross at Sir Michael Sobell House in Oxford, England drew up what he called the Ten Commandments for doctors dealing with the pain of cancer.

I previously mentioned as part of the nurse's responsibility symptom and pain management. Let me expound on that statement in this section. Symptom control can be divided into three main categories: 1) physical, e.g., pain, nausea, vomiting, etc.; 2) emotional, e.g., helping the client and family cope with the distress accompanying impending death; and 3) spiritual, an integral part of the program, with attention to human spiritual concerns a priority. Pain control varies as follows: 1) narcotics, 2) precision dosage and timing, 3) morphine, 4) the "American Hospice Mix" which contains morphine 5-90 mg's-, cherry syrup to 10 mls, and Compazine 5 mgs. (This is derived from the "Brompton's Cocktail" used in Britain, which is a liquid form of heroin, cocaine, alcohol, syrup, and chloroform water), and 5) hypnotics, and 6) adjuvant drugs (e.g., phenothiazines). Addiction is not an issue in a Hospice; the quality of the life remaining for the client is the key and real issue. Since the major concern of the Hospice is to keep the client alert and responsive at the same time pain and nausea free, the prescribed drugs are not given prn (whenever necessary) as is the usual method of dispensing pain medications. The proper time to give a dying client pain medication is before the client feels any pain, eliminating, therefore, the anxiety of the expectation of the pain. This requires close monitoring and continuity of care and personnel. The client will usually then remain as comfortable and peaceful as possible until he or she dies. For many clients "it is not death they fear, but unspecified, unlimited pain" (Lowell). Thus, how the pain medication is given is far more important than what is actually given.

Another key to the success of the Hospice movement is the lack of restriction in the area of visiting clients confined to the "non-ideal" Hospice outside the home. No restrictions are placed on the volume of visitors, as long as the client can tolerate it, nor the age of visitors including infants and small children; even pets are allowed to visit if that will add to the client's peace and comfort, and no restrictions are placed on visitors as to time, since time is very precious to the dying person. Recent studies have shown that survivors who do not view the body at the close of their loved one's life have difficulty in separating from the dead and can become long-term, chronic grievers, making them susceptible to higher morbidity and mortality rates. Moreover, there is much to be learned from the dying that would be lost if they are kept isolated. It is the dying who teaches us the real meanings of life.

Hopefully, the Hospice movement is an alternative method of care for dying clients that is more positive and more humane. The hospice accepts the client's death as a natural end to the client's life. The hospice team assists the client and family through the various stages of dying and the experiences associated with death, after first coming to grips with their own attitudes, concepts, and fears of death. The caring community helps and supports the client through their psychological and emotional reactions to dying, e.g., anger, guilt, shame, grief, depression, and acceptance; they recognize the client's coping mechanisms, e.g., denial, regression, and intellectualization as part of that dying client's

death process. They enforce guidelines for interacting with a dying client such as: maintaining the client's dignity (respect as a person), helping the client feel secure (a need for trust), and maintaining the client's hope (short-term goals). The Hospice team preserves the dying person's bill of rights which was established back in 1975. The Hospice approach eliminates the "living dead" syndrome so frequently seen in hospital settings (the dying client who waits alone, isolated, and already mourned by the family members in an emotionally and physically sterile environment). The control over one's life is important even if one knows that death is near and inevitable. The Hospice approach has added new dimensions to the nurse-dying client relationship.

The United States is on the verge of a Hospice proliferation. As the American health care system progresses away from the renowned hospital setting and moves back into a community-based system, as it is predicted, the Hospice movement will probably be strengthened. With or without the passage of the National Health Insurance Program, Hospice bills will still be paid for in part by such plans as Blue Cross/Blue Shield, Medicare, and Medicaid as it is currently being covered.

The scope of this paper thus far has been the Hospice as the future hope of the dying client's right to die with dignity. Drawbacks and imperfections in this system are also evident to the probing mind. One prime example is the setting up of the Hospice program as yet another specialty in the medical world. Nurses and physicians have departmentalized themselves into these specialties at the expense of the holistic approach to health care. Individual practitioners tend to remain in one chosen aspect of the field until burn-out occurs. Burn-out has also been experienced as a recurrent theme, especially in Hospice care. How long can one work with only the dying before depression or frustration sets in? An apparent solution to this problem would be a rotation schedule for medical and nursing staffs to prevent one from becoming too specialized or burnt-out. However, this would defeat the purpose of the commitment and continuity needed for Hospice care. As in every other area of the medical/nursing professions, the skills utilized can also become mechanical and rote in the Hospice movement. In Hospice care the need for hope, freshness, and diversity is apparent. Another possible drawback of this type of health care is an emotional over-involvement with the clients with the resultant: "each man's death diminishes me." How much can one give to another without paying a price? It is very draining to continually be supportive, accept the anger of others, and constantly face one's mortality. The caring required in Hospice care involves the willingness to do the unlovely -- a chief ingredient in this type of commitment (Hoskovec,<sup>8</sup> Administrator of St. Mary's Hospital, Bayside, Queens.) How long can this willingness thrive in a selfish society?

Another potential problem is the exploitation by commercial interests who would convert nursing homes, geriatric centers, and wards into "nominal" hospices in order to take advantage of a trend without any real preparation for, knowledge of, or commitment to the ideals of the hospice movement.

In summary, there has been change in the approach of the health care practitioners in the care of the terminally ill clients. The Hospice approach has been offered as an alternative to the existing pattern of avoidance and denial in the care of the dying. This approach is still in its formative years and has a long way to go before it is a widely accepted, preferred approach with minimal drawbacks that realizes the ideals of the Hospice movement as expressed by Dr. Saunders (1967): "You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die."

### **PHYSICIAN'S ATTITUDES**

The physician's task as stated by Edward Trudeau many years ago "to cure sometimes, to relieve often, to comfort always" seems to be the basis for care at Hospice. While the health team at Hospice consists of doctors, nurses, clergymen, social workers, psychiatrists, and volunteers, the most important person is still the physician. Too often the dying client feels abandoned by the doctor, that one has been written off as incurable -- therefore to be ignored as frequently as is possible by that one person whom they have come to trust and depend on. The Hospice doctors do not shun their clients or try to avoid "uncomfortable discussions" concerning their illness. The client knows the illness, prognosis, and what can be expected in the future. The client is not treated as a child but as an intelligent adult (assuming, of course, the client is an adult). The client is given functions to perform for and by himself for as long as possible. The client is also consulted in regards to the type and amount of pain reducing medication needed, the foods the client wants to eat, and when the client wants to sleep. The physicians sit down with the other members of the health care team on a regular basis to work out a plan of care for the client/family.

Taking care of the dying client has been part of medical treatment down through the ages. Maybe even now it should not have been excluded from the mainstream of medicine, since it has always been the responsibility of compassionate family physicians. Clients welcome continuity of care until their last breath (this is the "rule rather than the exception in Hospice" S. Lack), This editorial comment of John P. Callan, M.D. was refuted a few months later in the same journal by Sylvia A. Lack and William Fischer from the New Haven Hospice. In response, they commented that the ultimate goal of the hospice movement is reincorporation of timeless values and accepted methods into general medical care, and not to exclude the care of the dying from the mainstream of medicine. Technologically specialized curative medicine has catalyzed the growth of the hospice. Medical care as a natural balance. Part of our responsibility and commitment is to educate health professionals that a "care system" can coexist with a "cure system". This requires fundamental changes in attitude. Until these ultimate goals are realized, hospice care remains the only way to get competent and compassionate terminal medical care from a multidisciplinary team on a continuously available basis for care in the home and for bereavement follow-up.

Most hospices require the primary physician to remain responsible for the client's on-going plan of care.

Dr. Grebin, St. Mary's Hospice, said that one continuing uncertainty was the attitude of the profession and whether medical authorities would be prepared to make referrals. Some physicians "stand back from the idea that they cannot do anything" for the dying client, he declared, adding; that it was even more difficult for the physician to accept the fact that he had reached the end-point of treatment for a child.

Although the majority of practicing physicians may believe that it is better for them to be reticent with the dying, this opinion must be reconsidered in the light of the fact that an equally large proportion of lay people say that they would like to be told. On the surface, it seems quite perverse that 80 or 90% of physicians say that they rarely, if ever, tell clients that their illness is mortal (Oken 1961)<sup>13</sup> whereas about 80% of clients say they would like to be told (Gilbertsen & Wangenstein, 1961).<sup>1</sup> If a physician sees the question in rather unreal black and white terms of either pressing unpleasant news of impending death upon a client or keeping the client in happy ignorance of one's fate, this will sway the physician towards expressing an opinion against telling. This travesties the usual situation, however, where the dying person, with gathering doubts and clues, becomes increasingly suspicious that the end is near.

While physicians are trying to judge their clients' capacity to stand unpleasant news, many clients are equally making their intuitive judgments of whether their physician can bear sincere but difficult questions. (Hinton 1967).<sup>15</sup>

"Medicine tries to deny the need for pain, suffering, and death. So when they do appear, their victims, deprived of cultural support, have to face them unprepared. With the belief that the physician's task is to struggle against death, man has lost control over his own destiny. The medical profession has undermined the ability of people to manage their own lives" (Downie 1974).<sup>16</sup>

In a 1979 New York Times article, Hugh O'Haire<sup>17</sup> stated physicians agree that community-based treatment is not only more convenient but also welcome to clients because of some of the immediate but short-lived side effects of chemotherapy which make travel arduous. According to Dr. Roger Winn, chairman of a community-based outreach program of Memorial Sloan-Kettering Cancer Center, "doctors trained at large city-based medical centers are now able to carry out complex treatment regimens at the community level."

In the St. Luke's Hospice Pilot Project, the physician's role is summed up as follows:

- 1) To see referred clients and decide if they are hospice candidates;
- 2) To discuss with the client's physician if the client is to be picked up by the Team;
- 3) To prescribe a plan of care in coordination with the client's physician;
- 4) To see clients at least once a week and more frequently as needed;

- 5) To discuss the client's condition and plan of care with the Team once a week;
- 6) To see clients in the clinic;
- 7) To function as a consultant to other physicians who desire help in managing the symptoms of advanced cancer;
- 8) To assist with the writing of a research proposal related to the care of clients with advanced carcinoma.

## **PAIN CONTROL**

Mindful that not all pain suffered by the cancer client is due to the cancer, the hospice team seeks to control the pain so that it will not return. They strive for constant pain control! The client who experiences pain quickly learns to fear it. Most physicians in most conventional hospitals would prescribe pain relief medications every three to four hours whenever necessary (prn). By the time the client's pain medication arrives, the client is anxious, fearful, and probably angry. It then takes approximately one half hour for the medication to work and become effective, and even longer for the client to calm down. The client may get an hour worth of peace and then the vicious cycle begins again -- anticipation of the expected pain, the wait again, and the short-term relief.

The Hospice Team tries to avoid the waiting period for terminal clients. The client knows that there will not be a wait for relief-medication is administered in anticipation of the pain. If pain is eliminated, so is the fear of it. One does not become depressed or angry and one is able to derive the maximum relief from the drug given.

Non-narcotic drugs are used for as long as they are effective for each individual client. When relief is no longer attained, narcotic drugs are given. Fear of addiction is not a concern of the Hospice Team. The nurses will administer the smallest dose possible to accomplish the desired results an alert, pain-free client. Narcotics are usually administered with phenothiazines to potentiate the narcotic, to provide an antiemetic effect, and to alleviate anxiety.

At the New Haven Hospice, morphine dissolved in cherry syrup and phenothiazine is used for their clients. This is referred to as the "Hospice Mixture". Cocaine, alcohol, or chloroform water (components of the famous Brompton's Cocktail) is not deemed necessary. The Hospice staff also considers the use of heroin unnecessary in almost all cases.

The current debate about whether to permit the use of heroin or morphine by dying clients is symptomatic of a larger problem: the lack of a humane approach to the care of the incurably ill.

Dr. Robert Butler, Director of the National Institute on Aging, editorialized in 1977 that there are several factors to consider in dealing with the pain that characterizes the final days for many. Physicians must change their present practice of prescribing analgesics "as needed" and begin to prescribe small doses of effective pain-killers, gradually increasing the dose until the client is pain-free. The next dose should be given before the client may even think it is necessary. Thus, it is possible to erase both the memory and the fear of pain and to enable the client to review life and face death as serenely and comfortably as possible. Relief from pain is essential, and physicians should be able to prescribe the most effective drugs for their clients, including morphine and heroin.

With the current system of waiting for pain relief, clients actually require a higher dosage of medication than would ordinarily be indicated. With lower dosages required clients experienced less confusion and were afforded more "quality time" to talk and share feelings with friends and loved ones.

In another New York Times editorial by Harold M. Schmeck, Jr., it was suggested that the person dying of cancer usually needs protection from pain and fear. The treatment for pain and nausea is sometimes so cautious as to suggest that those in charge consider it either unimportant or immoral to deal thoroughly with the client's final agony.

The attitude appears to be changing, however; and the change was accelerated recently by the prodding of no less an agency than the White House.

The current focus is on two drug-- heroin and marijuana. The current attitude seems to be toward making these drugs more easily available, at least through legitimate research projects with clients. How far this will go and soon is not yet clear.

Heroin proved to be no more effective than morphine when administered orally at St. Christopher's Hospice as part of the Brompton mixture, a cocktail of narcotics, tranquilizers and alcohol given regularly to terminal cancer clients (Clark 1978).<sup>22</sup>

THC, the active ingredient in pot (marijuana) was tried as an antiemetic on a small group of clients receiving chemo therapy and found no better than conventional anti-nausea drugs. Dr. Peter Bourne, a President's special assistant health issues and an expert on narcotic abuse, and other experts believe that questions about the usefulness of heroin and marijuana can be resolved within the next few years.

The hospice at St. Luke's Hospital Center, New York City controls severe pain with methadone by mouth, giving it in initial doses of 5-10 mg. At 3-4 hour intervals. They have also had good results controlling pain with an oral solution consisting of morphine sulfate, 15 mg; cocaine hydrochloride, 10 mg. 95% alcohol, 1.7 ml. cherry syrup, 3.7 ml. and distilled water, 10 ml. It is given to many clients around the clock instead of prn (whenever necessary) because of the chronicity of their pain. Pain that is not allowed to reach peak intensity is easier to control.

Tylenol or aspirin sometimes is given with narcotics (though not all clients require narcotics) to potentiate their effects. Some clients require only APL's with codeine.

Analgesics may not always be needed to treat discomfort. What is essential is an assessment of the pain -- noting its site, duration, pattern, precipitating factors, and what relieves it.

## **TRAINING PROGRAMS FOR NURSES**

Nursing; students expressing an interest in thanatology can refer to professional journal articles, as well as register for elective courses in "Death and Dying" at their affiliated colleges. Some of the classic nursing and medical articles, books, workshops, and forum papers are listed in the Bibliography. It is impossible, of course, to list every article or book ever written on the hospice Movement or on "Death and Dying. However, a fairly good resource list has been compiled for your use.

For the graduate nurse the same opportunities exist as for the future nurses still in schools and colleges. The opportunity for further education in this contemporary field can also be found in the many in-service education programs/ workshops/conferences offered by their employers.

A copy of in-service education programs and workshops open to all nurses that are offered by various institutions in the New York area can be obtained by writing to the institutions directly. Speakers and sources of very pertinent information on thanatology and the hospice movement are not only diversified but also follow a much dispersed geographical pattern.

St. Vincent's hospital in Manhattan gave a pre-test/ personal questionnaire on one's perspectives on dying before beginning a workshop on the "Care of the Dying Client." It was a very enlightening experience for the participants. This particular workshop provided time for peer sharing and discussing of one's views on the subject. This was found to be a most beneficial aspect of the workshop by the many participants.

Continuing education in nursing, a future must, also provides the opportunity for educational advancement in the area of thanatology. Many community colleges, senior colleges, and hospitals offer C.E.U.'s (continuing education units) for the courses they present during the day, evening, or weekends.

Some institutions offer conferences on various topics such as hospice, or provide paid "professional leave days" for their nurses to attend conferences in other institutions.

Thus, nursing professionals have various opportunities to learn about, discuss, and update their professional and personal knowledge and skills.

## FOOTNOTES

1. Elisabeth Kubler-Ross, On Death and Dying (New York, 1969).
2. Leonard A. Liegner, "St. Christopher's Hospice, 1974," JAMA, 234:10 (December 8, 1975), 1048.
3. Cicely Saunders, "The Management of Terminal Illness," Hospital Publications, Ltd. (1967).
4. Sylvia A. Lack, "Philosophy and Organization of a Hospice Program," at the First National Training Conference for Physicians on Psychosocial Care of the Dying Patient (April 29 - May 1, 1976).
5. Vincent J. Dunigan, "Where the Dying Come to Live," The Catholic Digest (May, 1980), 89-92.
6. Sandol Stoddard, The Hospice Movement - A Better Way of Caring for the Dying (New York, 1978), p. 222.
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**HOPSICE APPENDIX I**

**INSTITUTIONS/ORGANIZATIONS**

**New York City**

Calvary Hospital  
Bronx, New York

St. Luke's – Roosevelt Hospital Center  
New York, New York

The Brooklyn Hospice  
The Metropolitan Jewish  
Geriatric Center  
Brooklyn, New York

St. Mary's Hospital  
Bayside, New York

North Shore University Hospital  
Manhasset, New York

Memorial Sloane-Kettering Cancer Center  
New York, New York

Mercy Hospital Hospice  
Rockville Centre, New York

Long Island Jewish-Hillside Medical Center  
New Hyde Park, New York

**New York State**

United Hospital  
Port Chester, New York

Mercy Hospital Hospice  
Rockville Centre, New York

Long Island Jewish-Hillside Medical Center  
New Hyde Park, New York

Hospice Care, Inc.  
New Hartford, New York

Our Lady of Lourdes Hospital  
Binghamton, New York

Hospice  
Planning and Educational  
Foundation of Westchester, Inc.  
White Plains, New York

## **HOSPICE APPENDIX II**

### **SUGGESTED DRUGS FOR USE AT A HOSPICE**

I. The aim of all therapy is relief of uncomfortable and unpleasant symptoms in all areas.

The proper dose of any medication is the effective dose for the individual patient.

### **ANALGESICS IN ADVANCED MALIGNANT DISEASE**

II. Aim to keep the patient both free of pain and fully alert.

#### **Method**

1. Chronic pain demands preventive therapy, which means that analgesics should be given regularly and prophylactically.
2. The right dose is that which gives relief for a reasonable period of time: a four-hourly interval may be regarded as the norm between administrations.
3. Non-narcotic analgesics should be tried in the first instance.
4. If ineffective - transfer to a stronger preparation.
5. Adjuvant medication is the rule rather than the exception. A phenothiazine such as prochlorperazine or chlorpromazine acts as an antiemetic and, possibly, potentiates analgesia.
6. Use oral medication whenever possible - it is easier to administer and does not necessitate inpatient treatment.

7. There is more to analgesia than analgesics. Some pain responds better to other forms of treatment, e.g., radiotherapy, cytotoxic drugs, nerve blocks, alone or in combination with analgesics.

8. Diversional therapy. The perception of pain requires both attention and consciousness. Diversional therapy - people to talk to, activities to attend, etc. - is, therefore, of great value.

9. Morphine, Methadone, and Dilaudid.

The use of these drugs does not guarantee success, particularly if the psychological component of pain is ignored.

### **PAIN CONTROL - Agents**

#### Mild Pain

Ascaf Tylenol for those intolerant of aspirin

#### Moderate Pain

ASA with codeine o/015 gm. Percodan

Talwin

(with or without compazine or thorazine syrup or tablet)

#### Severe Pain

Thorazine, Phenergan or Compazine tablet or syrup with:

Methadone

Dilaudid

Morphine

#### Anorexia

Rhubarb and soda

Tigan

Steroids: Prednisone, Dexamethasone

#### Nausea and Vomiting

Tigan

Compazine

Thorazine

Phenergan

#### Dyspnea

1) Bronchodilators

Tedral

Elixophyllin

Choledyl

Aminophylline suppository

2) Steroids

Prednisone  
Dexamethasone

3) Antibiotics (if infection is prominent feature)

4) Opiates

Morphine  
Codeine

5) Terminally only, when dryness will not be apparent to patient – atropine

Cough

ETH with codeine  
Benylin expectorant  
Glyceryl guaiacolate  
Codeine

Anxiety, Mental Distress

Valium, P.O., I.V.  
Thorazine  
Haldol  
Stelazine

Confusion

Thorazine P.O., I. M.  
Haldol with or without Artane

Depression

1) Attention to physical and mental distress

2) Steroids if indicated

3) Antidepressants:

Elavil  
Tofranil  
Ritalin

Insomnia

Chloral hydrate  
Phenergan  
Valium  
Dalmane  
Elavil

### Constipation

Colace

Senokot

Dulcolax tablets or suppository

Cascara, with or without milk of magnesia Enema

### Fungating Growths

1) Clean with peroxide

2) Bacitracin ointment

3) Non-adhesive dressing

### Frequency of Urination

1) Treatment of infection according to results of culture

2) Pyridium