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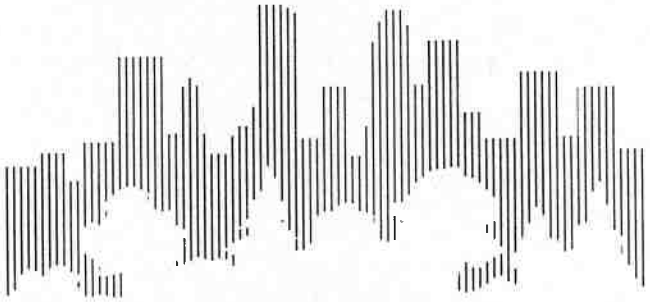

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David A. Larson

The Twin Cities Hospice Movement

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THE TWIN CITIES HOSPICE MOVEMENT: A HISTORICAL PERSPECTIVE

By

David A. Larson

A Thesis

Submitted to the Graduate Faculty

Of

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in Partial Fulfillment of the Requirements

for the Degree

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Minneapolis, Minnesota

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Master of Social Work
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CERTIFICATE OF APPROVAL

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Abstract

This historical study analyzed information about the development of hospice from ancient times to the modern hospice movement. In this study special attention is given to the modern hospice movement, which began in Britain in 1967, and began in the United States in 1974. The purpose of this historical study was to explore and discuss the development of hospice programs Twin Cities, MN, as compared to the hospice movement on a national level.

The study will describe the local hospice movement as seen through the experiences of three local death and dying activists. Throughout the study, the social ideals behind the hospice movement and the perceived social need the hospice movement sought to meet will be shown through the actions of the people involved in the hospice movement.

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Chapter One- Introduction

People living in America, for many years, continually heard that the dying experience for the terminally ill patient is often a negative experience. Death is undeniably a part of life, and how to make the dying process a meaningful part of the life cycle continues to be one of most important social questions of our time. From the ancient forms of hospice to the modern hospice movement, hospice activists and hospice programs have worked to develop an alternative form of health care that can answer this important social question. A hospice program would an alternative that would accept death and provide dying patients and their families with the support, education, and compassion to make death a positive experience (Beresford, 1993; Buckingham, 1996; Siebold, 1992).

Before the development of the first modern hospices in America, when a person was diagnosed with a terminal illness, there was an expectation of prolonged death, uncontrollable pain, suffering, isolation, and very little discussion about death and dying among family members and medical staff. Even today, the majority of terminally ill patients died in sterile institutional settings such as hospitals or nursing homes.

The patient and their families had little control over the quality or quantity of care received during the dying process. The concerns of the patient and family were often ignored, and the patient was very often subjected to intrusive, often unnecessary medical treatments. This course of medical treatment often caused additional disruption and confusion to a family already experiencing a major disruption in their family. The patient and family were often faced with confusing issues such as how, when, and where to die,

and often had little control over or input in these decisions (Beresford, 1993; Buckingham, 1996; Siebold, 1992.

Hospice programs began as grassroots movements in response to the social problem of death and dying in this country. The hospice movement was not the only solution to a better way of dying, but many people felt hospice was the solution that had the greatest potential to bring about change in the attitudes, values, and behaviors affecting dying persons and the people who cared for them.

Hospice programs were introduced in America 26 years ago, and since that time, hospice care in America has grown from an alternative health care movement to an accepted part of the American health care field. The development of the modern hospice offered patients and their families new hope that terminal illness and death need not be painful, impersonal, or create a situation that often causes the patient and family to feel isolated and confused. The modern hospice offered hope that death, while inevitable, need not be unendurable. The goal of the hospice program was to enable the dying patient and family to experience death as a meaningful part of the life cycle, a part of the life cycle that need not be filled with unnecessary pain, alienation, lack of control, or confusion (Beresford, 1993; Buckingham, 1996; Fish, 1997; Loconte, 1998; Siebold, 1992).

Hospice is not a place, but a concept of care. The care is most often provided in the home and allows families to be together when they need it most sharing the final days in peace, comfort, and dignity. The hospice program replaces an aggressive curative treatment approach of extending life at all costs with a caring based approach that enables the terminally ill patient to live well while dying. Those utilizing the hospice philosophy

work with an interdisciplinary team to address the full range of physical symptoms and psychosocial problems that the patient and family encounter as a terminal illness runs its course toward eventual death (Beresford, 1993, Buckingham, 1996; Fish, 1997; Loconte, 1998; Siebold, 1992).

Since the development of the first modern hospice program in the United States, this country has achieved tremendous progress in the care of the terminally ill, and now patients and their families have options in regard to how and where the terminally ill family member will be cared for during the dying process. Terminally ill patients no longer have to die in institutional settings. Hospice has provided the terminally ill with the opportunity to die at home, if that is what the family chooses to do.

Hospice programs, covered by Medicare since 1982, have become more popular over the years. The number of Medicare certified hospice programs grew from 31 in 1984, to over 2,154 in 1995 (Hoefler, 1997; Moore, 1998). This number consists of 699 home health agencies, 460 hospital based hospices, 19 skilled nursing facilities, and 679 freestanding hospices. In 1992, 154,000 Medicare decedents, about 10% of all recipients who died that year, made use of hospice services. Medicare and Medicaid provide hospice coverage in 44 states, and most private insurance companies, HMO's, and other managed care organizations include hospice care as a benefit (Hoefler, 1997; Hospice Association of America, 2000; Hospice Foundation of America, 2000; Moore, 1998).

Currently, there are approximately 3000 hospice programs, serving 540,000 patients every year in the United States. Most programs are home care programs, in which the hospice team enters the patient's home to provide medical and psychosocial support and guidance. As of 1998, 90% of all hospice care hours, regardless of program

design, were provided in the patient's home. Patients who utilize hospice services have various medical conditions; however, 71% percent of all patients, admitted into hospice programs in 1996, had conditions related to cancer. As of 1996, most patients receiving Medicare coverage for hospices were elderly, 68% were over the age of 65, and approximately 65% were male. With the more than 3000 hospices in America, patients now have a choice to spend the last weeks or months of their lives either in a institutional based hospice, or they can die at home with a support system consisting of family, friends, and the hospice team. In Minnesota, as of 1997, there were 61 Medicare certified hospices, serving 6,057 patients. In 1988, Minnesota dropped its Medicaid coverage of hospice programs. The demographics of people in Minnesota who access hospice programs reflect the national statistics, the majority have a form of cancer, are over age 65, and are male (Hoefler, 1997; Hospice Association of America, 2000; Hospice Foundation of America, 2000; Moore, 1998).

The hospice movement is grounded in history. The movement was shaped by people who thought there should be a more positive way to experience a prolonged death experience, and this idea is still timely in its appeal to the American population. Through increased understanding, recognition, and education, it is possible to make hospice care a more acceptable and widely known alternative for terminally ill patients and their families.

Although the hospice movement has not lived up to all its early ideals, the movement can claim certain ongoing accomplishments. The most notable accomplishment of the movement is that terminally ill patients are now less likely to end their days in an intrusive environment that lacks understanding of the dying process and

compassionate care. Dying patients are now more likely to die in an environment, which is usually a home, surrounded by friends and family. This allows to patient to live out their final days with dignity, control, and peace.

In our death denying culture we have been socialized to care for our dying family members in institutional settings, such nursing homes and hospitals. Because of this, people no longer died at home surrounded by their families. The message sent to many dying patients and their families, by the modern medical institutions, is that they should try and live as long as possible exhausting all medical interventions, any thing less would be seen as a failure. Hospice programs do not deny death and dying, but rather as an important piece of the life cycle.

Hospice is still struggling to overcome the perception that entering a hospice program is a choice to give up on life. The supporters of hospice assert that the hospice patient is not giving up on life, but rather taking control of the time that they have left. The hospice program assists the patient and family to make decisions that allow the patient to make their final days meaningful, which is not giving up on life, but rather living their remaining time left to the fullest.

This study was done to add to the existing knowledge about hospice programs, with the hope of encouraging more people to become aware of hospice. There are many more people with a terminal illness, who could benefit from the type of care provided by hospice programs. The goal of this study was to show how hospice developed in the Twin Cities, the values behind the movement, and benefits of utilizing a hospice program. It is the hope of the researcher that if there is ever in the need of terminal care

within their family, this study will add to the education and knowledge of the family, so that the family will be aware of the hospice option before they are in the dying crisis.

Chapter Two-Literature Review

This literature review will give a description of the historical development of hospice, from ancient times, to modern times, to national movement. It will then define the concept and philosophy of hospice, discuss how hospice works as a program, the role of the hospice team, and finally the role of social worker within the hospice program.

History of Hospice

Ancient Times

As the human race began to settle into organized communities, the need for separate structures to care for the sick or treat other social problems such as poverty and homelessness developed. There are ancient Greek documents that indicate the existence of separate structures for plague victims as early as 1134 BC (Benoliel, 1979; Davidson, 1978; Kulys & Davis, 1986; Seplowin & Seravalli, 1983; Siebold, 1992).

The health care system at this time was based on a belief in the healing powers of Aesculapius, a legendary physician who was defied in the 5th century BC. Therefore, most of the structures that existed to care for the sick or travel weary were called Aesculapia (Benoliel, 1979; Davidson, 1978; Kulys & Davis, 1986; Seplowin & Seravalli, 1983; Siebold, 1992).

There is an early account of a special facility for the dying in India around 225 BC. The emperor at the time opened a facility for religious pilgrims who traveled to India to visit the Ganges River. These pilgrims wanted to die in the river, and have their

ashes scattered in the river. The Indian emperor went on to build 18 such facilities (Cohen, 1979; Davidson, 1978; Siebold, 1992).

The motivation for caring for these people was religious in nature. It was believed that these people were thought to be under the protection of God, and deserved to be fed, clothed, and entertained without regard to their current situation or illness (Benoliel, 1979; Kulys & Davis, 1986; Seplowin & Seravalli, 1983; Siebold, 1992).

Christianity (and later Islam) more than other religions saw the care of the sick and dying as a sacred duty. By the end of the 4th century (300s AD) the church controlled Western medical care. It was the teachings of Christianity, with its emphasis on love and piety, which led to the growth of hospices for the poor, sick, and homeless (Cohen, 1979; Benoliel, 1979; Siebold, 1992).

Church doctrine gave bishops responsibility for providing services for the sick and travel weary. Bishops were instructed to welcome pilgrims into their homes or to find others in the community to perform these services. In AD 325 the Council of Nicea, a gathering of religious officials who established church doctrine, decreed that each bishop should establish a hospice in every city that had a cathedral. The Nicean decree was strengthened in AD 398 by the Council of Carthage, which urged that these facilities be maintained near the churches (Benoliel, 1979; Cohen, 1979; Rosen, 1963; Siebold, 1992).

It was the development of these ancient structures, which led to the development of early hostels, which would later be named hospices. The origins of hospice can be traced back to 475 AD and to even earlier times in Rome. There are numerous examples of these early hospices. One of the most famous was the Port of Rome begun in AD 475

by Fabiola, a Roman matron and a disciple of Jerome during the time of Emperor Julian the Apostate. Fabiola "witnessed the monasteries in the Holy Land, and brought them back with her to Italy, not only supporting hospices financially, but also serving as a nurse herself" (Kastenbaum, 1991, p. 108). The shelters that she built were open to travelers as well as the sick and dying (Benoliel, 1979; Corr & Corr, 1983; Kastenbaum, 1991; Kulys & Davis, 1986; Rosen, 1963; Seplowin & Seravalli, 1983; Siebold, 1979).

In Ireland (AD 500) St. Bridget provided care for the lame, lost, sick, and dying. The Great St. Bernard (AD 962) located in the Swiss Alps was staffed by Augustine monks. This facility, which is still in existence today, became the famous snow topped refuge where St. Bernard dogs were credited with saving the lives of travelers who had become lost or sick while traveling through the mountain passes (Benoliel, 1979; Cohen, 1979; Siebold, 1992).

Moslems also viewed care for the sick and dying as a religious duty. Their belief prompted them to build hospices throughout the Islamic world. Their knowledge of medical care was obtained from the ancient Greeks. Unlike the health care based on the religious beliefs of Christian culture, the Moslems created facilities that emphasized scientific principles. According to Cohen (1979), "In Baghdad, Cairo, Damascus, Cordova, and many other cities under their control, they provided ample, and frequently luxurious accommodations" (p. 16). By AD 1160 a visitor to Baghdad reported no less than 60 hospitals. The high level of medical care set by the Moslems persisted until the 15th century (Cohen, 1979; Siebold, 1992).

Middle Ages

For centuries, a hostel or hospice was a place for weakened or ill travelers to reside. The early form of hospice had its roots in the Middle Ages, and was found throughout Europe. These facilities offered shelter to any traveler, whether sick or well, and to the orphaned, the needy, and the dying (Burnham, 1999; Kulys & Davis, 1986; Loconte, 1998; Munley, 1983; Siebold, 1992).

These facilities were mostly run by religious orders. The Order of the Brothers Hospitalers of St. John of God was founded in Europe in the 16th century to care for those who were sick in body and in soul. During this time, early hospices emerged as a manifestation of a sacred worldview that led monks and nuns to act out of the belief that service to one's neighbor was a sign of love and dedication to God. Although the religious leaders were willing helpers, the medical efforts provided by them did little to reduce the occurrence of disease or illness. The church led medical practices were responsible for holding back scientific progress in the latter half of the Middle Ages (Burnham, 1999; Loconte, 1998; Kulys & Davis, 1986; Munley, 1983; Siebold, 1992).

Over the years, the medieval hospice evolved into a refuge where people could find care, comfort, and support during difficult times in their journey through life. The typical medieval hospice was a blend of guesthouse and infirmary where all travelers were given food, shelter, clothing, and medical care until they died or set out again, refreshed and renewed, on their journeys. The early form of hospice utilized a holistic approach to medical care; the notion was to care for mind, body, and spirit (Burnham, 1999; Kulys & Davis, 1986; Loconte, 1998; Munley, 1983; Proffitt, 1987; Siebold, 1992).

The Crusades, which began in the late 11th century and continued for several hundred years, were a milestone in the history of hospice. The early form of hospice experienced notable growth during the Crusades. It is with these early hospices, that people are the most familiar today. There were 750 early hospices in England by the 13th century, 40 in Paris, and 30 in Florence. These hospices were popular among the crusaders and travelers, who used them as places of rest and refuge (McNulty & Holderby, 1983; Siebold, 1992).

The Crusading Knights helped the religious orders to build hospices. The Hospitaller Knights established hospices in Europe and Syria, and the order of St. John in Jerusalem created hospices in Rhodes and Malta as well as other hospices in their command that were scattered throughout Europe. These hospices were not just for the male crusaders; the St. Mary Magdalene hospice was devoted to the care of women of the time (Cohen, 1979; Kutscher, 1983; McNulty & Holderby, 1983; Siebold, 1992).

Early Hospice

Another chapter in the history of hospice was in the 1800s. During this time, homes for the terminally ill were founded in Ireland, England, and France. The early hospices were a response to a perceived social need –as they were in the Middle Ages, when they were places of care for poor, sick, and pious wayfarers.

During the 19th century, hospices experienced a resurgence as they became more specialized in the care of the terminally ill. There were two reasons for the resurgence of hospices during this time. First, the potato famine in Ireland, and poverty and famine in other countries gave rise to the need for special care. Second, the religious leaders of the day felt that the secular hospitals tended to send terminally ill patients to other institutions

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that were thought to be even less sympathetic to the physical and spiritual needs of the terminally ill patient (Corr & Corr, 1983; Siebold, 1992).

Sister Mary Aikenhead founded a home in Dublin, Ireland, specifically to care for terminally ill patients. Aikenhead, a member of the Irish Sisters of Charity, is given credit for developing Our Lady's Hospice. Our Lady's Hospice, which opened in 1879, was the first facility created under religious orders to provide palliative care to terminally ill patients. Aikenhead considered death to be life's final pilgrimage, and she used the term hospice, to build upon the respite care of the ancient and middle ages form of hospice, which provided care to people on many of life's journeys. (Kohut & Kohut, 1984; Kulys & Davis, 1986; Munley, 1983; Proffitt, 1987; Siebold, 1979).

The spread of Sister Mary's philosophy led to the creation of hospices in England, France, and Australia. In 1874, Madame Garnier organized the Women of Calvary to create houses that would provide care for the dying and destitute in Paris, and in other regions of France. The far-reaching appeal of hospice programs resulted in the building of Sacred Heart Hospice in Australia. This facility was opened in 1890 by a branch of the Sisters of Charity (Kohut & Kohut, 1984; McNulty & Holderby, 1983; Siebold, 1992).

In England, hospice facilities flourished toward the beginning of the 20th century. Many of these early hospices survive to this day and contributed to the modern British hospice movement. In 1891, William Hoare of the Merchant Bankers of London was able to raise enough money to establish a home for the terminally ill. The Anglican Sisters ran this facility, which was named the Hostel of God. This facility is still in

operation today as a separate institution of the National Health Service (Kohut & Kohut, 1984; Munley, 1983; Siebold, 1979).

In 1893, St. Luke's House of the Dying Poor opened in Bayswater, London. The Methodist committee managed this facility. During this same time, Elizabeth Fry, a member of the English Sisters of Charity, fought for hospital and prison reform and she developed hospices through her religious group in London.

One of these hospices, St. Joseph's in London, opened at the turn of the century, and it was this hospice that Cicely Saunders took her first position as a nurse in 1958. It was Saunders' experiences, while caring for terminally ill patients at this facility that prompted her to develop an improved form of hospice. This was a hospice that would combine spiritual and emotional care, with the medical control of pain (Kohut & Kohut, 1984; McNulty & Holderby, 1983; Siebold, 1992).

Modern Hospice

In 1906, the Irish Sisters of Charity established St. Joseph's in London, England. It was as a nurse at St Joseph's Hospice that Cicely Saunders became intensively involved in improving methods of pain control for terminally ill cancer patients. Saunders began to see that what mattered most at the end of life was pain control, dignity in dying, and assisting the patient and family with the psychological and spiritual pain of death (Cohen, 1979; Siebold, 1992).

St. Joseph's existed to help dying patients manage their pain during terminal illness. The success of this facility, along with Saunders experience there, spurred the opening of St. Christopher's Hospice in 1967, in London. Saunders utilized local religious and community support to open St. Christopher's. It was at St. Christopher's

that Saunders began her historic work on the management of pain in terminally ill patients. Dr. Saunders' work was the beginning of the modern hospice movement. The modern hospice movement, with its emphasis on symptom control and on dying process, would soon spread to the United States (Kohut & Kohut, 1984; Kulys & Davis, 1986; Proffitt, 1987; Osterweis & Champagne, 1979; Munley, 1983; Rhymes, 1990; Siebold, 1992).

Dr. Saunders was discouraged by the disregard for the emotional, spiritual, and physical suffering that terminally ill patients often experienced in traditional medical facilities. The basis of her hospice philosophy quickly emerged: at home care, an interdisciplinary team of physicians, nurses, clergy, social workers, and many volunteers who would work together to meet the physical and emotional needs of the dying patient (Loconte, 1998; Millett, 1979).

Dr. Saunders, the founder of the modern hospice movement, provides a philosophical framework for a hospice by describing hospice as: " A place of meeting, physical and spiritual, doing and accepting, giving and receiving, all have to be brought together...The dying need the community, its help and fellowship.... The community needs the dying to make it think of eternal issues and to make it listen...We are debtors to those who can make us learn such things as to be gentle and to approach others with true attention and respect" (Kulys & Davis, 1986, p. 448).

According to Saunders philosophy, " The dying patient is viewed as accomplishing an important part of the life cycle. There is a realization that death is near, as well as a conscious acceptance of death as a part of life. Moreover, the support of the

dying persons and their families in their search for the meaning of life in the presence of death is a fundamental concept of hospice" (Kulys & Davis, 1986, p.448).

Saunders emphasized the need for effective symptom control, care of the patient and family as a unit, an interdisciplinary approach, the use of volunteers, a continuum of care including home care, continuity of care across different settings, and follow-up of the family members after the patient's death. These principles form the basis for the standards of hospice care in the United States set up by the Joint Commission on the Accreditation of Health Care Organizations and the National Hospice Organization (Proffitt, 1987; Rhymes, 1990; Siebold, 1992).

American Hospice

In America, the Dominican Sisters are credited with first caring for the dying who had nowhere else to go. Their facilities were patterned after England's in-patient models, which were established in the 1800s. Calvary Hospital for the dying was established in 1899, in New York City. In 1900, in Hawthrone, New York, a community of Catholic Sisters, the Hawthrone Dominicans, founded a facility that was dedicated to the care of the dying person. However, these early hospice programs did not develop into in-patient institutions. This was due in part to the desire of American families to care for their terminally ill family members at home as they had always done (Osterweis & Champagne, 1979; Proffitt, 1987; Siebold, 1992).

The United States modern hospice movement is based on the hospice model developed in Britain, which was developed by Dr. Saunders, at St. Christopher's hospice. The first American modern hospices were created because modern hospitals were unable

or unwilling to provide the necessary palliative services to terminally ill patients. The early hospices in America did not involve the family in the program.

During the early years of the movement, hospice programs believed the family had suffered enough and should be given permission to let go of the responsibility of caring for the dying patient. The early hospice programs were independent and community run. Most operated on low budgets, and relied heavily on donations, grants, and patient payments. Many consisted of a social worker and nurse who made home visits (Loconte, 1998; Siebold, 1992).

This early approach was changed with the development of modern American hospices, which were designed around the patient and the family. The modern programs included the family out of the belief that the family needed to be involved in the dying process. The goal was to involve the family in the care of the dying family member, with the support and knowledge of the hospice team. The majority of the care was provided in the home. In-patient facilities would be created in future years of hospice development (Proffitt, 1987; Munley, 1983; Siebold, 1992).

In the 1960s, the situation of dying people attracted renewed interest and research in American society. Dr. Saunders, in Britain and Dr. Elizabeth Kubler-Ross, in America were among many whom asserted that dying was a social problem, and they offered an alternative to traditional medical care. Saunders advocated the creation of modern hospice, a place that de-emphasized medical techniques and employed a holistic approach. Kubler-Ross asserted that most hospitals isolated dying patients and made their last days meaningless. Kubler-Ross recommended reuniting the dying patient with

family and friends to give them opportunities to discuss issues surrounding death and dying (Siebold, 1992; Strauss, 1975).

Publicity about St. Christopher's Hospice, and the increased interest in the terminally ill in the United States led to the future development of hospice in America. The publics renewed interest in the problem of death and dying was sparked by the book *On Death and Dying* (1969) by Dr. Elizabeth Kubler-Ross. This book brought the formerly taboo subject of death and dying into the American national debate. This book worked to heighten the awareness of this society's attitude toward death and dying, and the problems faced by individuals and families, who were experiencing a terminal illness (Siebold, 1992; Strauss, 1975).

The pioneering work of Saunders and Kubler-Ross, together with the work of Florence Wald, led to the founding of the first American modern hospice in New Haven, Connecticut in 1974. Florence Wald was a key figure in the development of American hospice movement. Wald worked closely with Saunders Kubler-Ross, asking each one to lecture at Yale. Wald's work eventually led to the development of an interdisciplinary team at Yale, to develop the first American modern hospice (Friedrich, 1999; Munley, 1983; Siebold, 1992). According to Friedrich (1999), "Wald established the first U.S. hospice, the Connecticut Hospice in Branford, which began providing home care in 1974 and in 1980 added an inpatient facility" (p. 1683).

Since the concept immigrated to the United States in the 1970's, its emphasis on a family centered approach, and its insistence that a dying person have a right to live as comfortably and as fully as possible, has attracted followers unwilling to accept the cultural forces compelling artificial segregation of death from life. The first American

hospices offered only in home services (Kohut & Kohut, 1984; Munley, 1983; Proffitt, 1987).

Since 1974, the hospice movement has grown rapidly in America. According to Kulys and Davis (1986), "From 1974 to 1986, hospices have experienced phenomenal growth in the United States, increasing from the first hospice founded in Connecticut in 1974 to over 1400 hospices in various stages of operation by 1984" (p. 448). The first American hospice was developed through grants from National Cancer Institute, private donations, and relied heavily on lay and professional volunteers and used a variety of organizational structures. By 1974, The National Cancer Institute had begun funding hospices, the first in Connecticut became a national model of home care for the terminally ill (Kulys & Davis, 1986; Kohut & Kohut, 1984; Loconte, 1998; Millett, 1979; Proffitt, 1987; Rhymes, 1990).

At the end of 1978 it was estimated that close to 200 hospice programs were in various stages of planning and development across the nation. The rapid interest and growth of hospices, at this time, led to the formation of the National Hospice Organization, in 1978. In 1978, four years after the opening of the 1st American hospice in Connecticut, the Pre-Forum Institute of the 105th Annual Forum of the National Conference on Social Welfare issued a report entitled "Hospice as a Social Health Care Institution", which defined hospice as:

> "A continuum of care, directed by professionals, designed to meet the needs and desires of those who have a very short time to live and for whom curative medicine has exhausted its possibilities. Hospice emphasizes relief from distress for the dying patient and family, without actively shortening or prolonging life.

This includes palliation of physical, psychological, and psychosocial symptoms of distress with a regular regime for alleviation of physical pain. All efforts are directed to the enrichment of living during the final days of life and are geared to provide ongoing opportunities for the dying to be involved in the life-caring community-surrounding them" (Kulys & Davis, 1986, p.448-449).

In 1979, the National Hospice organization published standards that were designed to serve as a basis for accrediting hospice programs. According to Kulys and Davis (1986), "these standards stated that in addition to the dying patient and their families, the members of the hospice team must include: the physician, nurse, social worker, patient care coordinator, volunteer coordinator, and clergy because no one individual or profession can meet all the needs of the dying patient and their families al the time" (p.449).

Also in 1979, the National Hospice Organization (United States) produced seven major principles that all national hospices should follow: 1) The focus of care encompasses the family as well as the patient. Hospice care is palliative rather than curative in nature. 2) A multidisciplinary professional team of physicians, nurses, home health aides, social workers, therapists, clergy, and volunteers provides the hospice care. 3) Hospice care is different from standard home care, hospital, and nursing home care in its extensive use of volunteers. 4) The services of hospice programs are available 24 hours a day, 7 days a week. 5) Hospice is a comprehensive program that provides care whether the patient is in the hospital, nursing home, or at home (Proffitt, 1987, p. 814-815).

By the mid-1980s the movement started to take off. As hospital costs escalated, Medicare joined the growing number of insurance companies that offered reimbursement to the hospice home- care approach.

In 1982, The Tax Equality and Fiscal Responsibility Act, which became operational in 1983, defined hospice as "nursing care by or under the supervision of a registered nurse; medical social services under the supervision of a physician; [and] counseling [including dietary counseling] with respect to care of the terminally ill patient and adjustment to his death" (Kulys & Davis, 1986, p. 449).

In 1983, Medicare began offering a hospice option to Medicare part A insurance to reimburse hospices for care of terminally ill patients who meet certain criteria. According to Rhymes (1990), " Growth of the hospice industry since then has been rapid, from 516 hospices in 1983 to more than 1700, including 600 Medicare-certified hospices, in the United States in 1989" (p. 369). In 1985, President Reagan signed legislation making the Medicare benefit a permanent part of the Medicare program (Loconte, 1998).

Medicare regulations stress home care and favor certain organizational structures. The imposition of these constraints on hospices when the movement was not well-formed and the tension between the former amateur status of hospice and its new status as a growth industry are among the reasons for the conflicts now apparent in the hospice movement.

Medicare covers all hospice services, in every state, and by Medicaid in 42 states. Most private insurers, HMOs, and managed care organizations also reimburse for hospice services. But even when patients have no insurance and can not afford to pay, many hospice programs will still provide care using funds raised from the community. Since

the focus of hospice care is on treating the patient, not the disease, there is no need to justify expenses, as is necessary in with regular medical care (Boon, 1998; Fish, 1997; Kulys & Davis, 1986; Loconte, 1998; Proffitt, 1987).

This federal legislation mandated that the home, in-patient, and bereavement components of the hospice program all be managed by the hospice. As a result, hospice care in America became a comprehensive service from the time of referral through the bereavement period. This benefit was historic for hospice for two reasons: "1) it provided reimbursement base for approximately 70 % of all hospice patients; and 2) it established the prepaid per capita reimbursement system, replacing the previous fee-for-service system. As a result, hospices are paid on a per diem basis, with the level of reimbursement based on the level of care required for the patient that particular day" (Proffitt, 1987, p.815).

The majority of early American hospices provided only one type of care- home care. According to the National Hospice Organization, "By 1984, over a thousand hospice programs were in operation across the United States". According to Brooks and Smyth-Staruch (1983), "By the end of 1984, a significant number of insurers included hospice as a benefit. A study completed by the Hospice Council for Northern Ohio demonstration the cost effectiveness of hospice care in addition to its psychosocial benefits" (Proffitt, 1987, p. 815).

According to Fish (1997), " The nation's 3,000 hospice programs currently tend to 15% of America's dying—approximately 390,000 deaths a year compared to the 1.3 million who die in hospitals", and that " the hospice programs could serve twice that

number, if hospice developed less intense and less expensive variations, it might be appropriate for anyone dying of a chronic illness--about 70 percent of the dying" (p.112).

According to the National Hospice Organization, "approximately 2,700 hospices in the United States and Puerto Rico served 390,000 patients in 1995, 78% of who had a cancer diagnosis. In fact, of the people dying of cancer in the United States, about one of every three receives hospice care." As of the close of 1998, there are now more than 3,000 hospice programs in the United States that serve approximately 450,000 patients, according to the most recent statistics of the National Hospice Organization (NHO), an advocacy and membership group based in Washington, D.C (Loconte, 1998; Moore, 1998; National Hospice Organization, 1997).

For the first 26 years of existence, hospice care in America grew from an alternative health care movement to an accepted part of the American health care field. There are numerous reasons for this happening, the most important being that hospice programs responded to perceived and real social need of improving manner in which terminally ill patients were cared for by the medical community.

Additionally, traditional medical institutions saw hospice programs as a way to produce more revenue, once hospice programs became certified under Medicare and Medicaid. As independent freestanding hospice programs began to operate, hospitals desired to be in on the activity, and many of the smaller, independent hospice programs were taken over by larger hospital systems.

There was also a sense of competition among hospitals, if one hospital had a hospice, the others in the area had to have a program. Further explanation of the competitive process in the hospice movement will appear in chapter four of this study.

The factors that influenced the movement of hospice programs from an alternative health movement to a accepted component of the American health care field is demonstrated in the discussion of the Twin Cities hospice movement in chapter four of this study (Bell, 2000; Beresford, 1983; Noller, 2000).

The hospice movement of today is a modern solution to an age-old problem, the alienation that people have to live with when dying. The modern hospice advocates the concept that no one should experience the alienation of death: not the patient, the family, or the caregivers (which may or may not be family members).

Definition of Hospice

Program

From the beginning, the hospice movement was considered a humanistic and holistic approach, which focused on the psychosocial as well as the physical needs of the patient and family. Hospice is the only medical institution designed solely for the care of the dying. Hospice provides an environment in which the patient can die, the program does not seek to prolong life or bring about a quicker death. A hospice program aims to provide care, comfort, and a supportive environment for the terminally ill patients and their families. Hospice is a comprehensive program that consists of three primary services: in-home care, in-patient care, and bereavement services (Boon, 1998; Buckingham, 1996; Fish, 1997; Friedrich, 1999; Kohut & Kohut, 1984; Loconte, 1998; MacDonald, 1991; Proffitt, 1987).

The hospice program seeks to provide a palliative and supportive service to meet the social, physical, spiritual, and psychological needs of the dying person and their family. These support services are done either directly or on a consulting basis with the

patient's physician, community public health nurse, or a visiting nurse. The hospice approach centers on helping the dying and their loved ones to maintain the dignity and humanness of the dying process while providing proper medical and nursing care (Buckingham, 1996; Cohen, 1979; Kohut & Kohut, 1984; Loconte, 1998; Millet, 1979; Munley, 1983; Proffitt, 1987).

The hospice program has as its main goal the reform of terminal care. The purpose of modern hospice is twofold: " 1) to help the terminally ill patient remain comfortable, alert, and able to participate in life as fully as possible for as long as possible until death occurs naturally and peacefully; and 2) to enable the family to remain lovingly attentive to the dying patient throughout the dying process" (Johnson, 1995, p. 252).

Pain Control

The primary emphasis of the program is to control the patient's pain and symptoms. The goal of treatment within a hospice program is to shift from curative measures to caring measures. By maintaining the patient as symptom and pain free as possible, hospice allows the patient to maintain control over his or her life, which will enable the patient and family to better cope with the impending death, with dignity and personal meaning. This environment allows the patient and family to deal with psychological issues and family concerns (Boon, 1998; Osterweis & Champagne, 1979; Millett, 1979, Rhymes, 1990).

The program seeks to assist patients who can no longer benefit from aggressive therapy and prolongation of life to die comfortably and to support their families and friends during bereavement. Palliative care and enhancing the quality of life are

emphasized, rather than cure of the disease or extending the patient's life. Pain control is stressed, but not only physical pain, emphasis is also placed on alleviating mental, emotional, social, and spiritual pain (Boon, 1998; Kulys & Davis, 1986; Rhymes, 1990).

Basic principles of hospice care, such as using adequate doses of medication around the clock to prevent rather than treat pain, are now widely accepted, though not universally used, in conventional care. Other innovations in pain control, including continuous or intermittent parenteral drug use and patient controlled analgesia, also were developed or first used extensively in hospice programs (Boon, 1998; Millett, 1979; Rhymes, 1990).

The ultimate functioning of the patient is the key concern of the hospice program. The hospice philosophy is that the best level of functioning, for the patient, depends on the control of pain and symptoms. The hospice program works to enable the patient to be as involved in their environment as possible and still control and manage their pain and symptoms. What level of awareness the patient has is up to the patient and their family to decide, and the hospice program is supportive of these wishes and does its best to reach the goal of the patient and family (Boon, 1998; Buckingham, 1996; Fish, 1997; IHHCD, 1978).

Family: Unit of Care

In the hospice program, the unit of care is considered to be the patient and the family. This unique medical approach is a family centered form of health care. The hospice program provides comfort and emotional support both to the patient and family members, before and during the bereavement period. Hospice programs also focus on family members and how the impending death is affecting them. Hospice provides many

services to family members, including bereavement services for up to a year after the patient's death. Families receive help in coping with their feelings, maintaining a fulfilling relationship with the patient, and planning for the future (Boon, 1998; Buckingham, 1996; Cohen, 1979; Fish, 1997; Friedrich, 1999; Loconte, 1998; Millet, 1979; Munley, 1983; Osterwesis & Champagne, 1979).

Counseling and therapy are important to hospice care. A severe illness or death can often expose underlying disagreements or unresolved problems. These issues are often complicated by guilt, resentment, and anger between caregivers and other family members and by physical and emotional stress on caregivers. Hospice programs provide counseling and assistance in coping with grief, fear, anxiety, and many social problems for the patient, caregivers, and family (Munley, 1983; Reese, et.al.; Rhymes, 1990).

Hospice is concerned with existing family ties during the dying process, and also with strengthening the family ties that may have been severed during life. Hospice seeks to empower the patient and family to repair any damaged family relationships, if that is a wish of the patient or family. Hospice does not separate the patient from the family; this practice makes hospice dramatically different from other health care institutions. Providing up to one year grief counseling to the survivors of the family member who died, is one way hospice shows its dedication to the family (Buckingham, 1996; IHHCD, 1978; Munley, 1983).

Dignity/Respect/Self- Determination

The hospice program strives to ensure that the dying patients and their families can maintain the dignity and humanness of the dying process while providing proper medical and nursing care. The absence of treatment coupled with the aggressive

symptom control plays a crucial role in allowing the patient to die with dignity, freedom, and self-respect. Hospice philosophy stresses patient self-determination and allows the patient and family to control the death accepting process. Hospice advocates for the dying person to be in their homes surrounded by important family members and friends, rather than in institutions surrounded by technology (Buckingham, 1996; Cohen, 1979; Munley, 1983; Osterweis & Champagne, 1979; Reese et al., 1999).

The hospice program is dedicated to meeting the needs and desires of the dying patient and their family. Hospice advocates the idea that a patient should be able to choose the environment in which they die. The patient has the right to be removed from an environment that produces feelings of helplessness, loneliness, and alienation. The goal of hospice is to remove the dying patient from " the bonds of pain, anxiety, guilt, loneliness, and fear of abandonment and impending separation" (Buckingham, 1996; Cohen, 1979; Munley, 1983; IHHCD, 1978).

Terminal Diagnosis

When the patient is given a terminal diagnosis of 6 months or less to live and agrees to hospice care, the patient gives up aggressive treatment of the disease. Once this is done, the patient will no longer receive chemotherapy or blood transfusions or be connected to any life sustaining medical equipment (Boon, 1998; Fish, 1997; Friedrich, 1999; Loconte, 1998).

Hospice care is designed for terminally ill patients neither to hasten death nor prolong life, and rejects curative medical efforts to prolong life for terminally ill patients. Hospice patients are at a point in the dying process where curative treatment has failed, and aggressive treatment is no longer productive or necessary. Patients are only accepted

into the hospice program after reasonable treatment efforts have been exhausted and the patient is specifically in need of supportive care during the dying process. These support services are done either directly or on a consulting basis with the patient's physician, community public health nurse, or a visiting nurse.

The absence of treatment coupled with the aggressive symptom control plays a crucial role in allowing the patient to die with dignity, freedom, and respect. By utilizing palliative medical interventions, the patient's symptoms are kept under control. The goal is to control the pain of the patient, allowing the patient to remain as involved in life as possible. As a result, the patients are able to live out their remaining time at home or in a home-like setting (Boon, 1998; Fish, 1997; Friedrich, 1999; Lonconte, 1998).

The referral process to hospice starts with a telephone call to a hospice provider. The telephone call can be made by the patient, family member, nurse, or hospital social worker. Although any interested party can make this call, a physician must sign a medical order, in order for the patient to receive hospice benefits.

After confirmation that the patient is terminally ill, an initial assessment of the needs of the patient and family is made by the hospice team. The initial assessment is used to develop a care plan for the patient. The care plan will specify what services family and friends will perform, and what services the hospice team will provide. Initially, the family is taught how to manage the patient's physical needs and symptoms, other than pain control. Once these needs have been addressed, the other team members can then focus on the patient's psychosocial, spiritual, financial, and other needs (Boon, 1998; Loconte; 1998; Proffitt, 1987).

The hospice team, physician, nurse, patient, and family determine what the individual and family care plan should include. Palliative care usually becomes the intervention of choice, with a committed focus on quality of life rather than duration of life. Hospice recognizes that death is a part of the human experience and seeks to make this phase as enriching an experience as possible for the patient as well as the family members (Boon, 1998; Loconte, 1998; Proffitt, 1987).

Hospice care is usually chosen as the preferred mode of care when the patient and family judge that the burdens of aggressive treatment are greater than the benefits that can be expected from it. The objective of care then changes from cure to a comfortable and satisfying death. Treatment is directed toward controlling pain, relieving other symptoms, and focusing on the special needs of the hospice patient and the patient's family (Boon, 1998; Kulys & Davis, 1986; McCraken & Gerdsen, 1991).

Family System

Having a family member diagnosed with a terminal illness affects the entire patient's family system. The diagnosis of a terminal illness has been observed to produce stress in both the patient and their family system. The patient and their family will encounter multiple and varied needs during the dying process. If the needs of the patient and their family members go unsatisfied, the resulting stress that is created can produce disruptions in their family system. These disruptions can create an environment that does not allow the patient to experience a positive death experience (Knapp & DelCampo, 1995; Kristjanson, 1989; Rosen, 1987; Schachter, 1992).

Conflicting views exist about whether a terminal diagnosis brings families together or produces stress that can distance them. However, the prevailing belief is that

a terminal illness can and does affect the entire family system, each member or individual being affected in varied ways and degrees. No family or family system lives through the death experience unchanged, and the dying experience can work to emphasize the role of each member in the family system (Knapp & DelCampo, 1995; Kristjanson, 1989; Rosen, 1987; Schachter, 1992).

Once the focus has shifted from curative to palliative care of the family member, the other members of the family system must decide where the palliative care will be performed. The other members of the family system must decide if they collectively have the resources to care for their dying family member in a home environment. This arrangement must be agreed upon by as many members of the patient's family as possible, because caring for a dying patient in a home environment requires high levels of involvement by the family members. The family members must be made aware that such a choice will increase their feelings of stress, and increase the demands and burdens placed upon by such a choice (Knapp & DelCampo, 1995; Kristjanson, 1989; Rosen, 1987; Schachter, 1992).

Many American families do choose to care for a terminally ill relative in a home setting. Research has shown that caring for a terminally ill family member can at times be stressful for family members, especially the family member who becomes the primary caregiver. This stress can be detrimental to the primary family caregiver. It is not unusual for the primary caregiver to have their physical and emotional health affected in a variety of ways (Austrom & Hendrie, 1992; Rosen, 1987).

When the family members become aware of the terminal diagnosis of another family member, and then chose to care for that family member in the home, the situation

can often become chaotic. The emotions of the patient and the family are often high, the patient and the family can become physically and emotionally exhausted. The role of the hospice workers is to assess the needs of the dying patient and family members on the first visit. Meeting and supporting the needs of the family members will be vital to providing the dying patient with an enriching death. The individual needs of the patient and family are determined through an initial assessment, traditionally performed by the hospice social worker (McCracken & Gerdsen, 1991; Rosen, 1987).

Hospice Team

Under the program of hospice, care to the dying patient and their family is provided through an innovative concept of an interdisciplinary team approach. The hospice team provides an array of services to assist the patient and their family during the last months of life. The basic hospice team usually consists of a physician, a hospice RN, a social worker, home health aides, clergy, as well as many volunteers. The team works, with the family, to relieve the physical, emotional, and spiritual pain involved in the dying process.

The hospice team meets regularly to develop, maintain, review, and implement the written care plan for the hospice patient. The team tries to work together to ensure that every team member is involved in the care of the patient and family. The team tries to ensure that every team member's role is included in the care of the patient.

All of the team members work to enable the terminally ill patient and their family come to terms with the complicated issues of death and dying. Throughout the program, the family has access to the team 24 hours a day 7 days a week. As a result, families are often prepared to share the time of death without a team member present (Boon, 1998;

Friedrich, 1999; Kulys & Davis, 1986; McCracken & Gersden, 1991; Moore, 1998; Proffitt, 1987; Reichel, 1999; Rhymes, 1990).

Social Work and Hospice Movement

The need for hospice care in America is rooted in the basic social work philosophy that the dignity of every human being must be preserved and that an individual should have control over his or her own destiny. The values and principles of social work are arguably the single greatest influence on the hospice theory and practice. Hospice can be seen as the embodiment of social work values principles and practice (Boon, 1998; Moore, 1998; Proffitt, 1987; Rhymes, 1990).

Specht and Craig (1982) define social work as " a profession with a dual purpose: to assist individuals and groups whose needs are not adequately met and to help change institutions so that they are more responsive to individual and group needs" (p.11). Their definition of social work applies equally to the mission of hospice programs, in which individuals and groups are terminally ill patients and their families, and the institution in need of change is traditional medical programs (Kulys & Davis, 1986; MacDonald, 1991; McDonnell, 1986; Proffitt, 1987; Quig, 1989; Rossman, 1977).

A holistic, ecological perspective that views people and the social environments they inhabit as constantly influencing one another characterize social work values and the tasks performed by the hospice social worker. Hospice social workers are concerned with the whole person and all of the aspects of a person that require care such as the spiritual, emotional, physical, and social dimensions. Hospice social workers work with the patient to enhance the patient's coping skills and independence, thus increasing the client's fit with the environment. This approach is based on the belief that competency is

best achieved when social work intervention is directed toward an ecological unit rather than toward an individual (Cox, 1992; Germain, 1979; MacDonald, 1991). "For social work, ecology appears to be a more useful metaphor than the older, medical disease metaphor because social work has always been committed to helping people and promoting more humane environments" (Germain & Getterman, 1980, p. 5).

Role of Social Work

Over the years, the prominence of the psychosocial component in hospice has led to the expectation that social workers occupy a distinct core position in the hospice interdisciplinary team. The role of the social worker must be viewed as integral to hospice care, and social workers' special skills and knowledge are indispensable to an effective hospice program (MacDonald, 1991; McDonnell, 1986; Quig, 1989; Rossman, 1977).

Social workers play a significant role on the hospice team, providing both direct services to the hospice patient and family and indirect services through administrative support. The psychosocial family assessment is typically completed by the social worker and presented at team meetings. The social worker's primary responsibility consists of counseling the patient, as well as the family members both before and after the patient's death (Beresford, 1993; MacDonald, 1991; McDonnell, 1986).

Additionally, the social worker may be called upon to organize numerous community resources and group bereavement services. The social worker may also take charge of the volunteer program and supervise the volunteers and offer them assistance in dealing with the patient and family. Finally, the social worker may be called upon to provide counseling and support services to team members who need assistance in coping

with their own grief in association of experiencing repeated losses of hospice patients (MacDonald, 1991; McDonnell, 1986; Quig, 1989; Rossman, 1977).

Training and Activities

The training of social workers enables them to help families deal with the financial and social implications of terminal illness. The interdisciplinary team will be much more able to carry out its tasks competently when the social worker's distinctive perspective is regularly evident (MacDonald, 1991; McDonnell, 1986; Quig, 1989; Rossman, 1977).

There are a variety of social work activities found in hospice programs including referral, brokerage, generic problem-solving services, emotionally supportive and bereavement counseling, psychosocial assessment, case management, and client advocacy (Kulys & Davis, 1986; MacDonald, 1991; McDonnell, 1986; Millett, 1983; Quig, 1989; Rossman, 1977).

During the course of treatment in the hospice program, the social worker utilizes the psychosocial assessment to determine what services the patient and the caregivers need access to, when access is needed, and for what time period. According to Rusnack, Schaefer, and Moxley (1988), "In hospice care, the social worker is concerned with the coping capacity of the client to deal with the tasks of daily living related to the demands of the disease process, the necessity for carrying out problem-solving activities, the management of painful emotions, the maintenance of optimal self-esteem, and the sustenance of optimal self-direction" (p.6).

Lack of Unique Social Work Role

Despite the prominence of the social work perspective in hospice and the considerable importance of hospice social work stressed in academic literature, almost none of the professional functions in hospice are performed exclusively by social workers. Kulys and Davis (1982) conducted a study of 34 hospices in Illinois to determine who performed the social services offered by the hospices.

Nurses, social workers, and nonprofessional volunteers were surveyed regarding 27 social service components of hospice care. The authors discovered that of the 27 components, social workers were substantially more active than nurses in only two activities-financial counseling and civil legal assistance. Kulys and Davis (1986), "concluded that social workers in Illinois hospices do not have a unique role in meeting the psychosocial needs of patients and their families, and that non-social workers regularly provide psychosocial care in hospices and that financial and civil legal assistance are the only functions that nurses and other team members attribute to hospice social work" (Kulys & Davis, 1986; MacDonald, 1991).

The study seemed to reveal that the social worker in a hospice program did not have a unique role in meeting the psychosocial needs of the patient and family. However, the social worker was more active than the nurses were and other staff in providing such services as referrals, financial services, legal assistance, and advocacy. The study seemed to indicate that in the area of psychosocial functioning, both nurses and social workers feel that this area falls in their area of expertise (Kulys & Davis, 1986; MacDonald, 1991).

In a study by Reese and Brown (1997), "it was discovered that hospice directors felt nurses are just as qualified as social workers to perform psychosocial functions. In a corresponding study of hospice home care, the home care nurses visited the patients five times as often as social workers, and seven times more often than clergy" (p.30).

Theoretical Framework

The theoretical framework for this study is the Ecological Life Model. In this study, the ecological life model will be defined as: "Living systems (people, individually and in groups) must try to maintain a positive fit with their environment. We all need appropriate inputs (like information, food, and resources) to maintain ourselves and develop" (Payne, 1997, p. 145). The basis for this approach is the belief that the highest level of functioning of the hospice patient and family is best achieved when the interventions are directed at the entire ecological unit rather than just the individual patient. The theory utilizes a humanistic approach, and views the patient, family, and their environment as the target of intervention (Cox, 1992; Gilgun, 1996; Payne, 1997).

In the hospice program, the social worker attempts to provide services to the patient and family, within the specific ecological environment that is identified by the family. Every hospice patient, family, and their living situation is unique. The hospice social worker, when entering the home, must take necessary steps to respect the family boundaries and rules specific to each hospice family (Cox, 1992; Gilgun, 1996; Knapp & Delcampo, 1995; Rosen, 1987).

In this study, the term family will be defined as: "A group of people who love and care for each other" (Turner, 1996, p. 605). Additionally, "Any relative or individual who has significant personal ties to the dying individual" (McCracken & Gersden, 1991,

p. 5). The term family system will be defined as consisting of: "Four major subsystems, including (1) spousal in the broadest sense; (2) parent-child; (3) sibling; and (4) the smallest subsystem, the individual" (Turner, 1996, p. 606).

Summary

We know that death and dying has been and still is a taboo topic for American families. Most of the dying and death processes continue to take place in institutional settings, such as hospitals and nursing homes. Americans continue to be tied to the medical model of handling death, a model that generally alienates the dying person, and does not provide care for the family system.

We know that hospice programs provide an alternative choice for patients and their families during the dying process. Hospice seeks to care for the family and patient as one care unit, thereby attending to the family as a system. Death and dying does cause stress on families and can affect the functioning of the family system.

Hospice programs continue to be underutilized in America. There are many barriers that are keeping patients and families for utilizing hospice. These barriers can be more complicated and far-reaching if the patient happens to be of a minority group. If these barriers could be eliminated, hospices could serve many more families in America that are experiencing the death of a family member.

The prominence of the psychosocial assessment and the intervention approach of seeing the whole family as the unit of care led to the expectation that the hospice social worker would have a distinct and integral role in the hospice team. However, as this study will demonstrate, the hospice social worker does not occupy a distinct role on the hospice team. Often times their role becomes blurred or overlaps with the role of the

hospice nurse. Hospice directors and nurses often feel that the nurses are equally qualified to perform the crucial psychosocial assessment and counseling services for the patient and family, leaving the social worker few activities that are exclusively their own (Kulys & Davis, 1982; Noller, 2000).

Chapter Three- Methodology

Introduction

The framework for this study utilizes the information gathered from the historical analysis of the hospice movement and is used to answer the research questions posed later in this chapter. Historical analysis will be defined in order to familiarize the reader with the model used for this study.

This methodology chapter will include the following divisions: the research questions posed in the study, a definitions of terms used in the study, the research design, subjects, procedure, data analysis, and the strengths and limitations of the study.

Research Questions

The research questions for this study are as follows: 1) What was the historical development of the ancient, early, modern, American, and local hospice movement? 2) What did the development of the Twin Cities hospice movement look like through the eyes of three local death and dying social activists? 3) What is the role of the social worker in hospice programs? 4) What does history teach us about the development of hospice?

Historical Analysis Defined

Historical analysis addresses the meaning of events by attempting to reconstruct the past, often in relation to a hypothesis. Historical analysis is a methodology that pertains to past events and is utilized as a way to establish facts and arriving at interpretations based on stated past events. Through the study of past and current events, historical analysis attempts to add rationality and meaning to society's current situation.

Historical analysis requires more than a collection of facts, historical analysis requires an interpretation of facts (Leedy, 1993; Rubin & Babbie, 1997).

Historical analysis seeks to identify patterns of events in society and strives to achieve a logical explanation for their existence. Historical analysis can be described as an examination of the cause and effect of events that make the facts meaningful in history (Leedy, 1993; Rubin & Babbbie, 1997).

Design

For this study, the research design utilized written records and studies of past and current developments in the hospice movement. The research design will discuss the development of hospice, and seek a logical explanation for the existence of the movement using as many sources as is possible.

The research design will utilize two forms of source materials, primary and secondary sources. The primary source materials for this study will include two transcribed personal interviews and a five-year report from the Minnesota Coalition for Terminal Care (Beresford, 1983). The secondary source materials for this study will include books, research studies, and professional and academic journals.

By using these source materials, this study will record a factual account of the development of the Twin Cities early hospice movement. Special attention will be given to the social aspects of dying, and how the response of certain people resulted in the development of the hospice movement in America, and the Twin Cities. This study will then use these source materials to answer the research questions.

Participants

The study utilized interviews of two persons who were involved in the early development of hospice programs in the Twin Cities, through their work with the Minnesota coalition for Terminal Care. The two people interviewed were chosen because of their early and important activities with the Minnesota Coalition for Terminal Care. Many of their activities led directly to the development of hospice programs in the Twin Cities and the Minnesota Hospice Organization.

The interviews will not involve a patient or family who are or have been personally involved in a hospice program. The research will follow all standard policies to protect the persons who give personal interviews. The interviews were conducted at the place of employment for each participant. The interview questions, interview procedure, and schedule used in this study appear in the appendix at the end of this study.

Procedure

The majority of the primary and secondary source materials used to complete this study will be gathered at the Augsburg College library, or by utilizing Clicnet. The information will be gathered from research studies, books, academic and professional journals, and agency reports and statistics. All of these materials will be gathered from local agencies or library search systems such as Silver Platter, Psychological Abstracts, Firstsearch, and Social Work Abstracts. All of these materials will be used to reconstruct past and current events pertaining to the modern and local hospice movement and will be used to answer the research questions.

Data Analysis

The design for analysis of the study will include a review of the historical development of the early and modern hospice movement, with special attention given to the hospice movement in America and the Twin Cities. The data will be used to describe the different time periods that shaped the development of hospice and influenced the experience of the patient and family involved in hospice programs. The data analysis will demonstrate how on a national and local level, the activities of a few key leaders and many dedicated supporters, led to the national and local hospice movement. The analysis will also describe the role of the social worker within the hospice team.

The data will be separated into categories that will allow for the data to be presented in a chronological sequence. By placing the data into chronological sequence, the study will seek to provide a simple timeline for the reader to follow, which will enable the reader to develop a clear picture of how hospice developed in America (Leedy, 1993; Rubin & Babbie, 1997).

Strengths and Limitations of Historical Analysis

Historical analysis can show the effects that certain social events can have upon individuals, families, and the environments that they must live in. The strength of this study will be derived from its interpretation of socially historical events in relationship of the hospice movement. The study will demonstrate how the hospice movement has had a positive impact on how patients and families deal with a terminal illness and how hospice programs and social workers enable the patient and family to function within their new environment.

This type of study may limit the researcher to produce their own research with new data and results. This type of study can also encounter difficulty when relying on

the personal biases, interpretations, and inferences of other author's work, which is used in this study. The personal biases, interpretations, and conclusions of the researcher can also hinder this study. Finally, this type of study can be limited by the personal biases, memory, or interpretation of past key events of the two persons interviewed for this study (Leedy, 1993; Rubin & Babbie, 1997).

Chapter Four-Findings and Discussion

Introduction

Dying is part of the living process. The issue of death and dying has been denied, hidden, ignored, and feared by our society. The death and dying movement was a response to this social condition. The death and dying movement was a health care reform, which grew from the social, political, and economic reaction to the depersonalization of the dying experience in America. The death and dying movement produced discussion and concern of how death touches us all, the treatment care of terminally ill, and how patients and families can be helped, and it was these discussions that led to the development of the health care reform called the hospice movement.

The hospice movement stemmed from increased social and personal dissatisfaction with the increased technological care of care of patients, which seemed to result in decreased care for human beings with terminal illness, the search for a unified approach to life and death that would combine medical knowledge with human and spiritual concerns, and by the vision, values, and skills of a few key leaders and numerous dedicated followers. The hospice movement's central goal was to search for a comprehensive approach to life and dying that would unite medical knowledge with faith, compassion, and the relief of pain (Foster, Wald, & Wald, 1978; Proffitt, 1987; Rhymes, 1990; Wald, Foster, & Wald, 1980).

National Movement

Hospice in America is approximately 26 years old, and in this time has grown from an alternative health care movement to an accepted part of the American health care field. Hospice was a grassroots effort, because people in communities heard about

hospice, believed there was a need for the special care of the dying, and worked together to form hospices. The hospice movement in America was the result of the activities, beliefs, and actions of many people (Buckingham, 1996; Rhymes, 1990).

In America, the Hospice Movement pioneered a new approach to dying. The philosophy of the movement focuses on psychosocial care, rather than solely on medical treatment. Hospice does practice palliative medicine, but it also attempts to assist patients and families to bring about emotional closure to life.

Since the hospice movement immigrated to the United States in the early 1970's, its emphasis on a family centered approach, and its insistence that dying persons have a right to live comfortably and as fully as possible, attracted many persons who were unwilling to accept the social and cultural forces producing the artificial segregation of death from life, and the segregation of the dying patient from their family (Rhymes, 1990; Proffitt, 1987).

Since 1974, when modern hospice began in this country, it has assisted and educated Americans to become more familiar with the dying process, a process that originally took place in the home, and has worked to return the dying experience to the home of the patient. With the modern hospice movement there has come a renewed experience and knowledge with the psychological and spiritual aspects of dying, and an increased ability to make peace with life and death.

The American hospice movement has its roots in early forms of hospice, and the modern hospice movement, which began in Europe. Early (ancient) hospices were institutions dedicated to providing care of the dying, and have existed for more than 2000 years. These early hospices evolved into institutions of spiritually inspired care and were

often operated by religious leaders or orders, and were dedicated to serving the Lord by providing loving care to the destitute, ill, and dying (Buckingham, 1996; Siebold, 1979; Rhymes, 1990).

Cicely Saunders

The early form of hospice (hostel) existed for hundreds of years, and remained until Dr. Saunders began the modern hospice movement by blending the early approach of spiritual service with modern techniques of pain relief, modern medical symptom management, and grief support for the terminally ill and their families. After working many years as a nurse, Saunders came to the belief that what mattered most at the end of life was pain control, dignity in dying, and help addressing the psychological and spiritual pain of death.

Dr. Saunders' desire was to combine the ancient and medieval hospice with modern medicine to produce a new form of hospice. Specifically, Saunders wanted to build upon the original ideas of hospice and the best possible pain medication, symptom control, and grief support for the terminally ill patient and their families. The modern hospice movement, with its emphasis on symptom control and on dying as a process, began in 1967, with the founding of St. Christopher's hospice in London by Dr. Saunders (Beresford, 1983, 1993; Buckingham, 1996; Rhymes, 1990; Siebold, 1979).

At St. Christopher's Hospice, Saunders and her staff recognized that the physical and social environments were as important to the patient and family as expert medical treatment. The first goal of Saunders and her staff at St. Christopher's was to ensure that patients were able to have their pain, and any other uncomfortable medical symptoms, under control. The second goal was to help assist the patient with the dying process.

This meant making the dying process a meaningful part of the life cycle. Finally, Saunders and her staff believed that dying is a uniquely important time in person's life. They viewed dying as the final stage of the human existence and as a normal and natural process (Buckingham, 1996; Beresford, 1982; Foster, et. al., 1979; Wald, et. al., 1980).

Elizabeth Kuber-Ross

During this same time, Dr. Elizabeth Kubler-Ross had begun what would become her famous work on death and dying education. Kubler- Ross began a death and dying seminar at the University of Colorado's medical school. She also spent many years interviewing more than 500 dying patients about their dying experience. Her work would culminate in her book *On Death and Dying* (Macmillan, 1969), which brought the formerly taboo subject of death into the American public debate. Dr. Kubler-Ross believed that helping a person pass from health to illness to death was and is a special form of care and treatment that can be learned through education (Beresford, 1982, 1993; Rhymes, 1990; Siebold, 1979).

Kubler-Ross added a new dimension to the care of the terminally ill with her perception of the human response to imminent death as a series of stages: denial, anger, depression, bargaining, and acceptance. In her book (Macmillan, 1969), Kubler-Ross made a plea for increased home care for terminally ill patients, as opposed to treatment in an institutional setting and argued that patients should have a choice and the opportunity to participate in the decisions that affect their life. Today many hospice workers have become comfortable with Kubler- Ross' death and dying philosophy, and have incorporated the philosophy with the basic philosophy of hospice, to ease physical and

psychological suffering (Buckingham, 1996; Hospice Association of America, 2000; Mango, 1990; Rhymes, 1990; Wald, Foster, & Wald, 1980).

Florence Wald

The first American hospice in America was based on the pioneering work of Dr. Saunders, Dr. Kubler-Ross, and Florence Wald. Wald and her professional and academic activities were directly responsible for the formation of the first modern hospice in America. In the mid-1960's, Wald was dean at Yale University's school of nursing, part of Yale-New Haven Medical Center.

In her experience, Wald had observed as medical practice and treatment seemed to move from a focus on people, to a focus on their diseases. It was disturbing to Wald that neither death nor the impact of treatment on patients and families was even being discussed. Wald felt that communication was lacking between caregivers and patients, and that patients were being excluded from the decision-making process.

Wald sought new ideas and solutions in the work of Dr. Saunders and Dr. Kubler-Ross, which led her to inviting both women to lecture at Yale. They each lectured separately, each presenting their own ideas about death and dying. Saunders focused on the spiritual and physical aspects of death and dying, and Kubler-Ross focused on the psychological aspects of death and dying.

In 1965, Wald invited Saunders to become a visiting facility member of the Yale School of Nursing for one term. In 1968, Wald took a sabbatical from Yale, and she took her entire family to London and spent an entire month at St. Christopher's Hospice caring for the dying. When Wald returned, she shared her experience with her colleagues, and

formed an interdisciplinary group to discuss the formation of hospice in America (Buckingham, 1996; Proffitt, 1987; Rhymes, 1990; Siebold, 1979).

The interdisciplinary group at Yale University, inspired by Dr. Saunders, visited St. Christopher's hospice one by one and began to plot their course for opening a hospice in America. These discussions began in 1971, and the interdisciplinary faculty team met once a week to determine how to bring hospice to America. These meetings eventually led to the first American hospice, which began in New Haven, Connecticut, in 1974.

The National Cancer Institute (NCI) funded The Connecticut Hospice for 3 years to develop a national demonstration center for home care for the terminally ill and their families. Many people involved with hospice feel that the New Haven hospice would not have survived without the support of the National Cancer Institute (Buckingham, 1996; Hospice Association of America, 2000; Proffitt, 1987; Rhymes, 1990; Siebold, 1979; Wald, et, al., 1980).

The Connecticut Hospice began offering home based care. This first hospice stressed care provided by the family and death at home made possible with the support of the hospice team. Most of the early American hospices' provided only the home care component. Eventually, Wald and her colleagues built an in-patient facility, but as the hospice movement grew in the United States, it has commonly focused on care and support in the patients' homes rather than in medical facilities. Some were run completely by volunteers, but most were operated by a combination of paid and volunteer professional staff, and used a variety of organizational structures (Beresford, 1993; Proffitt, 1987; Rhymes, 1990).

In 1982, federal legislation included a provision to create a Medicare hospice benefit in the Tax Equity and Fiscal Responsibility Act, which provided reimbursement for hospice care for the elderly. Under the Act, Congress mandated that the home care, in-patient, and bereavement components of the hospice program all be managed by the hospice program. As a result, hospice care in America became a comprehensive service from the time of referral through the bereavement period.

In 1983, Medicare began offering a hospice option to Medicare Part A insurance to reimburse hospice programs for care of terminally ill patients who met certain criteria. Although insurance coverage for hospice is available through Medicare and in 44 other states under Medicaid, most private insurance plans, HMOs, and other managed care organizations include hospice as a benefit (Kulys & Davis, 1986; Proffitt, 1987; Hospice Association of America, 2000; Rhymes, 1990).

Medicare hospice participation has grown dramatically, since 1982. By the mid-1993, over 1600 hospice programs were in operation in the United States, serving over 200,000 patients a year. The number of hospices participating in Medicare increased from 31 in 1984 to 1,857 in 1995. This number consists of 699 home health agency-based hospices, 460 hospital-based hospices, 19 skilled facility-based hospices, and 679 freestanding hospices. Currently, there are more than 3,100 hospice programs in the United States including Puerto Rico and Guam. Hospice programs cared for nearly 540,000 people in the United States in 1998 (Hospice Association of America, 2000; Hospice Foundation of America, 2000).

Twin Cities Development

Many of the events and people involved with the hospice movement in the Twin Cities are similar to the Modern Hospice and National Hospice movement. The hospice development in the Twin Cities was the result of the dedicated and influential work of a few key leaders and numerous volunteers. The full range of persons, events, and organizations involved in the development of hospice in the Twin Cities is too great for the scope of this paper. Therefore, development of the hospice movement in the Twin Cities will be told through the eyes of three local health care activists.

The story of the development of the local hospice movement will be told from the point of view of a few individuals, such as Howard Bell, Gail Noller, and Larry Beresford, all of whom were involved in the Minnesota Coalition for Terminal Care. It is the hope of the researcher that these sources will be adequate for the reader to arrive at a fairly clear picture of how hospice developed in the Twin Cities.

Personal Experience

Similar to the persons involved with the modern hospice movement and the national hospice movement, many of the people involved locally had personal or professional experiences with terminal illness and death and dying, which drew them into the work of hospice development.

Howard Bell

Howard Bell, the future first director of the Minnesota Coalition for Terminal Care, the first hospice chaplain at Bethesda Lutheran Hospital Hospice, and the first director of the hospice program at Abbott Northwestern Hospital, had some early and influential experiences that drew him to future work in hospice.

Bell gave numerous examples of early experiences with death, dying, and terminal illness. When Bell was 1 year old, he had an aunt die of cancer, and as he grew up, his family continually told him stories of how his aunt, after 2 years, died a horrible and painful death from cancer. Bell stated that "he learned early on to fear death from cancer, because cancer meant you died in a horrible manner" (Bell, 2000, p. 1).

When Bell was 8 years old, his grandmother died in his home from a heart attack. This event took place on an evening when Bell had been punished for making his grandmother tired because he refused to help her clean the house. From this early developmental experience, Bell feels that he felt great guilt from his grandmother's death. To relieve his guilt, Bell participated in years of counseling, therapy, journaling, and autobiographical work in his seminary education.

When Bell was in the 2nd grade, he lost a classmate to leukemia and when he was in the 4th grade he was a pallbearer for a childhood friend. When Bell was 16 years old, he experienced the death of his girlfriend to an unexpected medical condition. Her death and the following funeral were difficult for Bell; however, he feels this experience made death even more real to him.

When Bell was in college, he was involved in an internship at a small parish. During his experience at his church, Bell took part in 5 funerals, one for a 2-year-old baby, 2 for elderly persons, and one for a 19-year-old female. Bell felt that these experiences thrust him into the roles of grief and spiritual counselor. Bell feels that "his experiences of death with his aunt, grandmother, childhood friends, his girlfriend's unexpected death, and his internship at the church created in him a greater interest in death, perhaps more than the average person" (Bell, 2000, p1-2).

In 1971, Bell moved unto Yale University Divinity School, located near New Haven, Connecticut. At Yale, Bell enrolled in an interdisciplinary course that dealt with the chronically ill patient. This course was the creation of Edward Dobihal, Director of Religious Ministries at Yale New Haven Hospital. Dobihal was considered an early expert on the issues of death, dying, and terminal care. Dobihal became a member of the interdisciplinary team set up by Florence Wald, which would eventually be responsible for the development of the first modern hospice in America. Dobihal's wife, Shirley Dobihal, was one of the first hospice nurses in the New Haven program. This course was Bell's first exposure to working with a dying patient, and exposed him to key leaders in the future development of the first hospice program in the United States (Bell, 2000; Beresford, 1982).

Bell's experiences at Yale exposed him to teachers and professors who had worked with and learned from Dr. Saunders. Bell was in New Haven during the infancy of the first hospice in America, and this made Bell feel he really wanted to be apart of the hospice movement. Bell stated, "his experiences at Yale connected him to his past, and to his future, and that he felt blessed to be apart of the infancy of the American hospice movement"(Bell, 2000, p.3-4).

Gail Noller

Gail Noller's involvement in the development of the local hospice movement began when she was the Director of Social Services at Mount Sinai Hospital in 1975. As the director, Noller was asked by the chief medical director to respond to a family's complaint involving the death of their mother. The family felt that the medical staff

handled their mother's death and the interactions with family members in an insufficient manner. (Bell, 2000; Beresford, 1982; Noller, 2000)

Noller interviewed the family at the hospital, and they expressed their concern over how their loved one had been cared for at the hospital. The family felt their mother's treatment had been mismanaged while she was in the intensive care unit. At first, Noller assumed it was a medical mismanagement, but the family told her they were talking about the lack of emotional and psychological care their mother received in the unit. The family felt that they were not included in her care plan, were often kept out of her room, and that no one told them their mother was close to death (Beresford, 1982; Noller, 2000).

Noller's experience with this family at the hospital and the experience of her own father's death, prompted Noller and a colleague to meet with the medical director, the hospital administrator, the director of nursing, and the director of nurse education to discuss how the family's situation had been handled. All of these people agreed there were changes that needed to be made, and agreed to meet on a regular basis to discuss the issues of death and dying at the hospital.

The result of these interdisciplinary team meetings was a hospital program on death and dying. Howard Bell stated "in my opinion this was the first "hospice" program in the Twin Cities, even though it was not an official hospice program, I feel the program was groundbreaking when it began in 1974" (Bell, 2000, p. 10). This program conducted death education seminars, provided counseling for patients and families, conducted support groups, an formulated a ethics committee to investigate medical practices involving terminally ill patients.

After learning more about the death and dying program at Mount Sinai Hospital, which was started by Gail Noller, a social worker, and Rhoda Leven, a psychologist, Bell invited the two women to speak to the people involved with the Eight Weeks to Live-Eight Weeks to die program. Some of the issues that were discussed were then presented to the original group, of local medical people, that came together to discuss the creation of the Minnesota Coalition for Terminal Care (Bell, 2000; Beresford, 1982; Noller, 2000).

Hugh Harrison

Hugh Harrison, was on the board of the YMCA, and was a local philanthropist. Harrison's wife died, of a terminal illness, at Abbott Northwestern hospital in 1976. Due to Harrison's financial security he was able to provide the best possible dying experience to his wife. He was able to bring his wife home, because he could afford private nurses and quality home-care. Harrison was interested in the work of Bell and the Eight Weeks program, and wanted to further the work of Bell and support the movement (Bell, 2000; Beresford, 1982).

Harrison gave a grant to the YMCA program, which provided the YMCA program with the start up cost of the Coalition and allowed Bell to travel to the hospice in New Haven to attend a hospice symposium. The purpose of this symposia was to find other people in the country who were also doing hospice work. The symposium also had as goal to start a national organization to coordinate the American hospice movement. The coordinators of the symposia asked for volunteers to be board members for the National Hospice Organization (Bell, 2000; Beresford, 1982).

At a later date, Harrison then gave more money to the YMCA, and stated that he wanted the funds to be used to pay Bell's salary for one year to develop his work in the area of death and dying. The money was to be used to allow Bell to do want ever he thought necessary to develop his ideas. This money eventually allowed Bell to volunteer as a hospice chaplain, in a local hospice program (Bell, 2000; Beresford, 1982).

Larry Beresford

Beresford's involvement in the local hospice movement began in 1978, when he was in his final years of study at the University of Minnesota. He responded to a job posting for a part-time secretarial position with the Minnesota Coalition for Terminal Care. Beresford was curious about the organization's name, and wanted to find out why anyone would choose to specialize in issues such as terminal illness, death, and dying. A week after he started the position, his brother-in-law died suddenly, and his mother was diagnosed with kidney cancer. Four months later, his mother died in the hospital. This was after four months of cancer treatment, chemotherapy, and surgery. Hospice care was never offered to his family (Beresford, 1993).

Beresford stated "these were the first two deaths to have a big impact on my life, the first two to involve people who were close to me and not yet elderly, and they shattered the composure of my family" (1993, p.xvi). After these experiences, Beresford became more active and interested in the activities of the Coalition. Beresford went on to author the Coalition's five-year report, along with other books discussing hospice, which are cited extensively throughout this study.

Local Hospice Development

In 1972, Bell accepted a position at the University of Minnesota's YMCA program. Bell was to be the program director of the Big Brothers-Big Sisters program,

which was entitled Project Motivation. During the interview, Bell told the staff of his interest in death and dying. The staff informed Bell he could dedicate 2/3 of his time to the program director responsibilities and 1/3 of his time to pursue his interest in death and dying. For the first time since leaving Yale, Bell felt he had the support to return in some way to his interest in hospice. Bell set out trying to duplicate the death and dying course he experienced at Yale. He felt the best way to do this was to meet with persons and resources in the local academic and medical community (Bell, 2000; Beresford, 1982).

Bell's interest in the field of death and dying led him to contact local experts in the field. Bell began by meeting with John Brantner, who was a psychologist at the University of Minnesota Medical school, and had taught a death education course in the past. According to Bell, "Brantner was considered by many to be a local expert on the area of death education. Brantner was also on the board of the University YMCA, so in many ways he became a mentor to me" (Bell, 2000, p.6). Brantner once said, "Interest in death issues was here (Twin Cities) very early" (Beresford, 1982, p.2).

Bell also spent time with Robert Slater, who was the Director of Mortuary Science. Bell considered him to be a forward thinker in the area of death education and also to be a knowledgeable and compassionate man, and felt he would be an invaluable resource to the development of hospice in the Twin Cities. Slater was quoted as saying, "outside of Harvard University and Massachusetts General Hospital, there is no greater concentration of death and thanatology experts than in the Twin Cities" (Beresford, 1982, p. 2).

Bell also developed a relationship with Robert Fulton, who was a professor of sociology, and was currently teaching courses on death education. Fulton was also the

editor of the Journal of Education, and was considered an international expert on death education. Bell also became involved with members of the seminary who expressed interest in the areas of death, dying and hospice (Bell, 2000; Beresford, 1982).

Bell fostered these partnerships and friendships for the first two years he was at the University of Minnesota YMCA. He spent time trying to the foster the idea that his course should be taught at the various programs at the University that would benefit from such as course. Bell failed at his early attempts, and was unable to get his course apart of any program at the University. Bell decided to have a staff retreat for the members of the Project Motivation program, to determine what if anything could be done to further his work in the area of death education (Bell, 2000; Beresford, 1982).

The week before the staff retreat, one of the interns discovered a lump in her breast. By the end of the week the tumor was removed and discovered to be benign, and she joined the rest of the staff at the retreat. At the retreat, the intern told the staff, "I have lived my entire life based on an expected future. I had never thought, before last Wednesday, about the possibility that I would die before my future was realized...I never thought about the concept of living for the moment, because I was trying to accomplish my education, get married, and live for the future. We need to find a way to accomplish what Howard is trying do, we need to find a way to have college students experience what I have experienced, without actually being ill...I wish it would be possible for every person to have the experience I had" (Bell, 2000, p. 7). Doug Wallace, who was the Executive Director of the University YMCA from 1969-1978, responded to the female intern by saying "Why not?" (Beresford, 1982, p. 5).

After the staff worked for two hours they had designed the seminar program- Eight Weeks to Live- Eight Weeks to Die. Bell became the first director of the Eight Weeks program offered in the spring of 1975. According to Beresford, "the Eight Weeks program strengthened the relationships Bell had developed with people involved in the death and dying movement" (1982, p. 5). Bell stated, "they were all saying, why don't you organize something, and many were suggesting that a hospice program be established in the Twin Cities" (Beresford, 1982, p.5).

In the 3rd year of the Eight Weeks to Live-Eight Weeks to Die Program, a female student had been referred to Bell because of her interest in death and dying. She informed Bell that she wanted to start a hospice program in the Twin Cities. Bell told her he did not know where to begin, and that he lacked the resources and access to start such a program. Bell asked the student to help draft a proposal. According to Bell, "they sat down and dreamed up the Coalition for Terminal Care" (Beresford, 1982, p. 6).

According to Bell, "we didn't feel the need to start a hospice, but we had all these people who already were or wanted to improve the care of the dying, but who did not know each other" (Beresford, 1982, p.6). The first proposal for the Coalition, dated March 1977, was mailed to a dozen Minnesota leaders in the field. Bell and the student sent the twelve letters asking the leaders if they, or anybody they knew, was interested in starting a hospice or a coalition of professionals interested in improving the care of the terminally ill.

Bell and his student wanted to see what would happen if they could pool the best minds in the Twin Cites together around the issue of improving the care of the terminally ill. They wanted to bring together all of these leaders for an exchange of ideas and

information. According to Beresford (1982), "of the twelve interested parties, only Brantner recommended against the Coalition, because he feared that institutionalizing new efforts would kill the spirit of the movement" (p.6).

From the original twelve letters sent out, Bell and his student gathered twenty-eight names of persons who expressed interest in such a coalition. On June 7th, 1977, Bell and his student scheduled an organizational meeting at Lutheran Deaconess Hospital, and seventy-seven people attended, to hear the proposal for a Minneapolis hospice (Bell, 2000; Beresford, 1982).

Bell asked Noller if she was interested in getting involved in doing more work related to terminal illness and care in the Twin Cities area. Noller and Bell decided to meet and discuss any future involvement on the part of Noller. Noller and her colleague were invited to speak at the first meeting.

Once on board with the Coalition, Bell asked Noller to chair a committee of the Coalition entitled the Hospice Collaboration Committee. The purpose of this hospice committee was to offer support and education to local people interested in starting hospice programs. The committee was designed to be objective and not affiliated with any one hospice program, with the goal of avoiding competition. Based on the early beginnings of hospice programs in the Twin Cities, Noller decided that the committee needed to respond to the growth in the area. In the late 1970's the committee became the Minnesota Hospice Organization (Bell, 2000; Noller, 2000).

In addition to Noller and her colleague, three additional people were on the speaking agenda. Ida Martinson, who had experience performing home care with terminally ill children and their families. Elaf Gus Nelson, who was a Lutheran minister

with experience in family practice and had also chaired a task force for the National Lutheran Church of America entitled-Terminal Illness Ministry Extension (TIME). Nelson had spent time studying the newly formed hospice programs in New Haven and Montreal. It was Nelson's desire to develop a twelve-bed hospice program at Lutheran Deaconess hospital. In fact, he presented his plan that day.

Finally, Robert Buck Green, who was a medical oncologist in a local metro area clinic. Green felt that no plans to start a hospice should take place that day. Green felt that many of the people in attendance did not have adequate information to get such a program off the ground. Green said he was willing to sponsor an educational conference. In February 1978, there was a conference entitled The Care of Persons with a limited Lifespan (Bell, 2000; Beresford, 1982).

Green put this program together and a committee was formed, and the coalition was formed that day. Bell stated "that many people were offended by Nelson's idea for a hospice at Lutheran Deaconess hospital, because many people felt that they were already doing hospice"(Bell, 2000, p.13). According to Bell, "North Memorial hospital had a plan for a hospice, Mount Sinai had their plan, Abbott Northwestern had their plan", and "it quickly became apparent that there was going to be a competitive environment in the local hospice movement. It seemed to me that every hospital wanted one, and they wanted to be the first, and they wanted to have the best one" (Bell, 2000, p. 13).

This meeting was the beginning of the Minnesota Coalition for Terminal Care. The meeting generated excitement among those in attendance, many of which were considering hospice programs at their hospitals. The meeting sparked further collaboration among people involved with many death and dying programs throughout

the Twin Cities. The Coalition eventually developed into the Minnesota Coalition for Death Education and Support, which is still in operation today, and is where Gail Noller continues her current work in the area of death and dying (Noller, 2000).

Around this same time, Bell had heard about a hospice program being developed at Bethesda Lutheran Medical Center, in St. Paul. Bell took time to visit with its founders Carmian Seifert, Robert Brown. Bell eventually decided to attend a national symposium on the national hospice movement with Seifert and Brown (Bell, 2000; Beresford, 1982).

While at this symposium, Brown volunteered to be on the national founding board, Seifert volunteered to be on the accreditation committee, and Bell volunteered for the reimbursement and licensure committee. According to Bell, " Siefert had a major role in identifying what constituted hospice programs on a national scale. In this way, there were at least 3 local persons who worked to shape national hospice programs" (Bell, 2000, p.15-16).

Brown and Siefert eventually announced that they had started a hospice program at Bethesda Hospital on July 1st, 1977, which can be considered the official start of hospice in the Twin Cities. This was strictly a home-care-based hospice, with Siefert as the first hospice home-care nurse. By March 1st, Bethesda opened the first in-patient hospice. Bethesda Hospital was the first program in the Twin Cities to receive the Medicare waiver. Because Bell's salary was being paid by the Harrison grant, Bell asked Brown and Siefert if he could volunteer as their hospice chaplain, and he became their hospice chaplain from July 1st, 1978 through June 30th, 1979 (Bell, 2000, p. 16; Noller, 2000, p.2).

Bethesda opened their home-based hospice in 1977 and their in-patient hospice in 1978, then North Memorial opened their hospice the same year, as well as Methodist Hospital and Fairview Hospital. Gus Nelson never developed his hospice program at Lutheran Deaconess Hospital, but he was responsible for the 3 separate hospice programs opening at the Fairview Hospitals (Southdale, Riverside, and Burnsville). The University of Minnesota Hospital did not open a hospice program during this time period. According to Bell, "there was resistance on the part of the hospital and the oncology staff to tie cancer to closely to dying" (Bell, 2000, p.18).

At the close of his time at Bethesda, the grant paying for Bell was running out, and he was unsure want to do. He knew he did not want to go back to the YMCA, after his experience at Bethesda hospital. Bell was eventually invited to come to Abbott Northwestern Hospital and start their hospice program, and accepted the position on October 1st, 1979 (Bell, 2000, p. 17).

By April 1st, 1980, Bell began operating a 4-bed hospice at Abbott Northwestern hospital. The hospice was an in-patient unit, which was part of the hospital's home-care program. The hospice program utilized public health home nursing services, and was operated by an interdisciplinary team. By the time Bell opened the hospice program at Abbott Northwestern hospital, it was the 13th hospital-based hospice in the Twin Cities (Bell, 2000, p. 17-18).

Local Competitiveness

According to Bell, a philosophical split developed between himself, Brown, and Siefert (Bethesda), because they felt Bell was fostering a multiplication of hospital-based hospice programs. According Bell, "Brown and Siefert felt that the Twin Cities would be

better served if hospice programs operated by geographic regions, and that the Coalition was producing small hospice programs that would eventually fail, would not be sufficient to meet the local demand, and would not provide the same quality of care as the larger hospital-based programs" (Bell, 2000, p. 19).

Hospices grew at an amazing rate in the Twin Cities area, which mirrored the growth rate of hospices across the nation. Noller stated "one of the reasons the Twin Cities was asked to host the 1983 National Hospice meeting was because of the phenomenal growth of hospice programs in the Twin Cities in such a short time. I think every hospital, without exception, had a hospice program" (Noller, 2000, p.4).

When asked why he thought hospice programs grew so fast in the Twin Cities, Bell responded by saying, "if a person was simply cynical, they would say pure and simple competition. If North Memorial had to have one, Methodist had to have one, and Bethesda had to have one" (2000, p.23). Bell also felt "there was large amounts of money behind the local hospice movement, especially on the part of large hospital systems, and that is way hospice programs became more mainstream", and "on a national level there was money to be made due the hospice certification by Medicare and Medicaid (2000, p. 23). Noller responded to this question by stating, "there was a lot of interest, and maybe even jealousy, about how did Bethesda already start a hospice, when the rest of us are just getting our feet wet" (Noller, 2000, p. 2).

Bell felt that there was a rift forming between large hospital-based programs and smaller programs. There was a sense that to ensure quality and cost-effectiveness these programs would need to be merged into larger hospital systems. Bell felt the same split

was taking place nationally, and the belief was in our economy the bigger the program the better (Bell, 2000).

On the other hand, Bell also stated, " that the amazing growth of hospice in the Twin Cities was due to the amazing convergence of many positive, compassionate, concerned people, would had passion and belief in the care of the terminally ill." Bell felt that "the Minnesota Coalition of Terminal Care simply organized the local energy, passion, and commitment of the local hospice players. Bell stated "the Coalition was able to do this because it was not a competitive environment, and was not affiliated with any outside agency (Bell, 2000, p27-28).

Bell invited John Brantner to speak at the 2nd annual hospice symposium in 1979. Branter presented 10 challenges to the hospice movement. According to Brantner, "that in 10 years we should not see hospice programs anymore, because the proper care of the dying should be incorporated into all hospitals and nursing homes. Branter continued, "that special hospice programs are not needed, because hospice is a philosophy of care that is appropriate for all dying patients" (Bell, 2000, p. 22).

Brantner felt "that this care did not have to take place in a separate unit, it should happen wherever people are dying. And that we should not separate the living from the dying, we are all living and we are all dying. The original philosophy of hospice had failed, and that people were more interested in self-preservation and creating hospice programs" (Bell, 2000, p. 22).

Gail Noller was one of many people nationally and locally that agreed with Brantner. In the early 1980's, Noller backed off from her work with the Minnesota Hospice Organization. Noller was not interested in performing exclusively hospice work.

She stated that "the hospice movement was no longer a health care alternative, it was really becoming more of a medical institution, and I am not sure that was the best way to have the movement evolve" (Noller, 2000, p. 6). She wanted to have an impact on the entire health care system, and wanted to work to create a health system that would be more sensitive to the needs of all dying patients (Noller, 2000, p.2).

Medicare Hospice Benefit

In 1982, The National Hospice Organization was instrumental in getting Congress to pass the hospice Medicare Benefit. Bell felt that this legislation was more beneficial to the larger hospice programs. Bell felt the requirement that a hospice could not be certified for the Medicare benefit unless it could perform home care was influential in deciding what programs could take advantage of the Medicare benefit. Bell felt the motivation for this legislation was to control costs, by having terminally ill people at home. This is where the 80/20 provision came into play, which meant that in any certified hospice, no more than 20% of the patient's final days could be in-patient, and 80% had to be home-based. The hospice program that Bell had begun at Abbott Northwester could not be certified for the benefit. Bell testified on a national level against this requirement (Bell, 2000, p.20).

The Medicare legislation provides hospice programs with a daily per diem for every day the patient is in the hospice program. The hospice program receives a fixed amount and then must provided all of the hospice services mandated by the legislation. Noller stated "it is similar to the DRG system in most hospitals, there is a set payment, and the full range of services must be provided, regardless of actual individual patient expense" (Noller, 2000, p. 8).

Bell left the Abbott Northwestern hospice in 1987, and the program still was not Medicare certified, but Bell felt that they were still able to run a quality program without the benefit. Noller feels that the compassionate people, locally and nationally, slowing were forced out of the movement by the National hospice Organization, federal legislation, and hospice regulations. According to Noller, "After people like Bell, Siefert, and myself jump started the movement, we moved onto other social issues or concerns, like these people are apt to do (Noller, 2000, p. 5).

Role of Social Worker

I asked Noller what she thought the role of the hospice social worker currently is in the Twin Cities. Although Noller is no longer a hospice social worker, she currently meets with the hospice team at Methodist hospital and also does contract counseling with the Allina system hospice program. Therefore her response is based on past experience and her current activity with these programs.

Noller responded by saying, "You know my thought about what ought to be the social worker's current role in hospice is probably quite different than what it currently is. I think it ought to be a counseling role" (Noller, 2000, p.6). "I think originally those of us who were social workers and involved in the movement did everything. You know there was no clear role for the social worker" (Noller, 2000, p. 6). Noller remembers doing volunteer training, volunteer supervision, training of nurses, producing policies and procedures, leading team meetings, meeting with families in their homes, performing family counseling (Noller, 2000, p. 6).

Noller feels that the current role of the hospice social worker become more specialized, but necessarily more defined, with the developing regulations and policies produced by the National Hospice Organization and Medicare legislation (Noller, 2000).

Noller stated that currently she believes that "today most social workers in Minnesota hospice programs do not perform much patient or family counseling, or psychosocial assessments, which mirrors the results of the Kulys and Davis study (1982) and the Reese and Brown study (1997). Both of these studies discovered that often times the role of the social worker was blurred with the role of the hospice nurse, and that the hospice nurses were territorial in regards to their patients. Many of the hospice managers who responded in these studies felt that their hospice nurses were just as qualified to perform the psychosocial assessment or necessary patient and family counseling.

The two studies also reported findings that the blurred role of the hospice social worker can at times produce competition with the hospice nurses, who are often territorial in regards to their patients. When informed of the results of these two studies, Noller affirmed similar situations for social workers in Twin Cities hospice programs.

Noller stated, "instead social workers find themselves performing financial and legal assistance, referrals to outside therapists and community resources, and quick assessments to determine the nature of referrals." This statement also confirms or is line with the Kulys and Davis study (1982) and the Reese and Brown Study (1997). Additionally, Noller believes that "most hospice social workers would complain about being overworked, but not because they are doing the family work they initially intended to do, instead it is performing the tasks I mentioned earlier" (Noller, 2000, p. 6).

According to Noller "When I was the Director of Social Services at Mount Sinai, I would advocate for the social workers, stating that I felt social workers skills were being underutilized, but I feel as time went on, the situation only worsen for the social workers. The length of hospital stays became shorter and shorter, as hospitals became more concerned with early discharge, which meant the social worker became a discharge planner, not a counselor. I feel a similar comparison can be made to the current role of Twin cities hospice social workers, because the goal of the hospice programs are to get the family and patient plugged into as many outside resources as possible, thereby saving the agency money" (Noller, 2000, p. 6-7).

Noller discussed the role of the hospice social worker in providing bereavement services to the family, which is a major component of the hospice philosophy. She feels that local hospice social workers do not get really involved in bereavement services. In her opinion, the main reason is that bereavement services do not receive any direct reimbursement services. Noller stated "Bereavement services are required for Medicare funding and by state legislation. The legislation requires bereavement services for 13 months, which is through the anniversary date of the death plus 1 month" (Noller, 2000, p. 7).

Noller thinks that most of the bereavement services are provided by hospice volunteers and student interns, which reduces the out-of-pocket expense to the hospice program. The volunteers and students are used to perform bereavement telephone calling, and to send out monthly mailings to those families deemed low risk based on the assessment. A Bereavement Director usually supervises the students and volunteers. Only families, who are determined to be high-risk, receive in person counseling from

volunteers or students. According to Noller, only a small few group of families receive bereavement counseling from an agency social worker or psychologist (Noller, 2000, p.7).

Noller stated that "I would say most social workers who came into this field thought they would spend extensive time providing direct services to dying patients and their families. There was probably an expectation of performing a more traditional counseling role, but they discover this is not their role. I think chaplains do more direct counseling than the social workers actually do. Although I think there is pressure on the hospice social worker to do it all, most social workers become frustrated that they often can not do it all, they do not have the time. Most have large caseloads, and spend the majority of their time do task orientated roles, and do not even have time to perform direct counseling" (Noller, 2000, p. 9).

The hospice social workers that Noller comes in professional contact with tell her they are frustrated with their current blurred role on the hospice team. Their main concern is that the role of the hospice nurse often erodes their role, and that the two roles often overlap (Noller, 2000, p.11).

History Lesson

What has this historical study taught us about hospice movements and hospice programs? Most importantly, it has taught that when concerned, active people perceive a problem in society or in their community it is possible to create a solution. Both the national and local hospice movements were started as grassroots solutions to the social problem of death and dying. The people involved with these movements wanted to create a better system to care for terminally ill patients and their families.

Both the national and local movements have also taught us that in order to create a solution for improved care for terminally ill patients and their families, it is necessary to have the support of numerous academic, religious, medical, and philanthropic people. Both the national and local movements relied upon the talents, skills, knowledge, and financial support of numerous people.

As is often the case with any social movement, many of the people involved with the hospice movements had professional or personal experience with the social problem they are working to change. The people mentioned in this study, both national and local had experienced numerous events surrounding death and ding. Some experienced a improperly handled death in their family, some experienced numerous improperly handled deaths in their professional career, and all of them seem to have experiences with what they perceived as an impersonal medical community.

Finally, the history of the national and local hospice movements have taught us that for any social movement to be successful there needs to be considered time spent on educating the public about the particular movement's issues. The Minnesota Coalition for Terminal Care was initially created as a way to discuss, challenge, and educate people about death and dying issues. The Minnesota Hospice Organization, which was at one time part of the Coalition, was simply one result of the initial work of the people involved with the Coalition. Bell recalls that the original intent of the Coalition was not to start hospice programs, the programs were simply a result of their work with people in the community.

Conclusion

The development of the local hospice movement mirrored the modern and U.S. hospice movements. All of the movements began as grassroots movements, started by social activists and concerned people in the community. All of these people were seeking a solution to the perceived social problem of death, dying, and the care of the terminally ill. All of the people had personal and/or professional experiences that drew them to the work of improving the conditions of terminally ill people, and the education of the public about death and dying issues. All of these activists felt that terminally ill patients and their families were not receiving adequate education, psychosocial support, or medical treatment from the traditional medical institutions.

Similar to the social activists involved with the modern and U.S. hospice movements, the local activists felt the care of the terminally ill was an unmet social need in the Twin Cities. These people initially set out to educate and support terminally ill patients and their families about death issues. The end result of their efforts was the development of hospice programs in the Twin Cities.

The local activist began by gathering locally concerned experts in the fields of medicine, nursing, and death and dying education to discuss the necessary improvement of the care of dying patients and to discuss possible solutions. They began to educate themselves and the community in the area of death and dying and in the possible alternative that hospice programs could offer. Their basic goal was to educate the public about terminal illness and terminal care; their ultimate goal was to create hospice programs that would meet the needs of the terminally ill patients and their families. It was their hope that adequate education and hospice services could be available to

families before there was a terminal illness in their family, so that they would be aware of the possible benefits of hospice to their families, before their family was in a crisis.

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APPENDIX

APPENDIX A
INTERVIEW QUESTIONS

To be asked by researcher:

1) Tell me when did you first become involved with hospice? What, from your point of view, were the significant events or people involved in the development of hospice in the Twin Cities?
2) When did you begin/end your role as a hospice social worker?
3) How do you think the role of the hospice social worker changed during that time?
4) What was unique about your role as a hospice social worker?
5) How was your role as a hospice social worker unique or different from other hospice team members?
6) What activities do you feel you performed, as a hospice social worker, which were the most beneficial for the patient or family?
7) What do you think a hospice patient and family needs most from a hospice social worker?
8) How much did the patient's environment and relationship issues become an area of attention for you? How important is the psychosocial assessment to the patient and family?
9) How important do you feel the bereavement services are for the family?

APPENDIX B
RECRUITMENT SCRIPT:

Hello my name is David Larson. I am a M.S.W. student at Augsburg College. I am doing a historical study on the development of the hospice movement in the Twin Cities. I am trying to locate and interview persons who were involved with the early stages of the local hospice movement, and are interested in sharing their unique experiences. I am also trying to locate and interview social workers that were involved with early hospice programs in the Twin Cities, who are interested in sharing their unique experiences as early hospice social workers in the Twin Cities.

The process would involve a 60-minute interview, in which I would ask you a few questions. I would like to audiotape the interview for the purpose of transcription. To ensure confidentiality, the audiotapes will be destroyed when I have finished my study and paper.

Participation in this study would be completely voluntary. Possible indirect benefits include helping to improve the understanding of the researcher and other social work practitioners about your experiences as a hospice social worker. You may also benefit by reflecting on these events and sharing your experience as a hospice activist.

If yes, when is a good time and location to conduct interview?

If no, thank you for your time.

APPENDIX C
CONFIDENTIALITY FORM:

This research study may include sensitive and confidential information about study participants. This information is shared with you confidentially for the purpose of being transcribed. By signing this form you are agreeing to not reveal names, identifying information, or any other content of the interviews.

Name of Transcriptionist	Date
Participant Signature	Date

Consent Form :

Thesis Title: A historical study of the hospice movement in the Twin Cities, and the role of the hospice social worker in the hospice program.

You are invited to participate in my research study designed to analyze the development of hospice in the Twin cities, and the role of the hospice social worker in hospice programs. David A. Larson is conducting this research study in the partial fulfillment of the Master of Social Work thesis requirement at Augsburg College.

What will happen during the study?

The study consists of one audiotaped interview lasting approximately 60 minutes. A Master of Social Work student, David A. Larson, who is working on his thesis, will conduct the interview. You will be asked to relate stories about your experience as a hospice activist, and or a hospice social worker, during the formative years of the Twin Cities hospice movement. After the interview is complete, I will have the audiotaped interview transcribed and use it in support of my study. Your responses to the interview questions will be used as support data for the completion of my study.

Are there any risks?

The risk to you should be minimal. However, it is possible that the researcher can not foresee any or all risks that could arise from your participation. There is the possibility of some degree of invasion of your privacy. If at any point during the interview you feel to uncomfortable to go on, you may stop the interview without consequence. If you have concerns about any risks, the researcher will discuss them with you, before the interview begins, or before you sign the consent form.

Are there any benefits?

It is possible that you could experience an enhanced sense of well being or satisfaction as a result of telling your story. The researcher will also benefit from your wisdom and experience in regards to this study's topic.

When and where will the interview be conducted?

The interview will be scheduled at a time and place that is convenient for you (interviewee). Interviews will be conducted in person.

Who will have access to the interview material?

A trained transcriptionist will transcribe the audiotaped interview. The tape will be destroyed after the study is complete. The transcriptionist will be required to sign a confidentiality form to ensure your privacy. The transcripts will be shared with the researcher's thesis advisor during the process of completing the thesis, and also with several members of a research team who will be reading, interpreting, and reflecting on the transcripts. All information is confidential. However, the researcher can not guarantee anonymity due to the small sample size, but will make every effort to maintain anonymity. Transcripts will be destroyed no later than August 1st, 2000.

What if you change your mind?

You are free to end the interview, withdraw from the study, or refuse permission for the use of your interview or transcripts at any time. Your decision whether or not to participate will not affect your current or future relationship with Augsburg College. Before you sign the consent form, please ask any questions on aspects of the study that are unclear. I will attempt to answer any questions you may have prior to, during, or following the study. If I am unable to answer any of your questions to your satisfaction, you may also call my thesis advisor, Laura Boisen at (612) 330-1439.

AUTHORIZATION:

I,_____, have read this consent form and decided to participate in the research project described above. My signature indicates that I give my permission for information I provide during the interview to be transcribed and utilized for the thesis project. I will be given a copy of this form for my records.

_____ _____

Signature of Participant Date

_____

Complete Address and telephone # (for the purposes of contacting you, if necessary)

IN ADDITION:

I consent to an audiotaped interview:

_____ _____

Signature of Participant Date

I consent to direct quotes from my interview:

_____ _____

Signature of Participant Date

If you have any further questions you can reach me at:

David A. Larson
Augsburg College, MSW student
Telephone: W: (612) 874-1030 or Cell phone (651) 402-8639

MINNESOTA COALITION FOR DEATH EDUCATION AND SUPPORT
P.O. BOX 50651
MINNEAPOLIS, MN 55405
612 - 391 - 3051

March 9, 2000

To Whom It Concerns:

This letter grants David Larson, a Masters student in Social Work at Augsburg College, access to the records and archives of the Minnesota Coalition for Death Education and Support.

Gail A. Noller
Treasurer and Board Member