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# The Utilization of Hospice Care in Assisting to Meet the Needs of Family Members of Terminally Ill Patients

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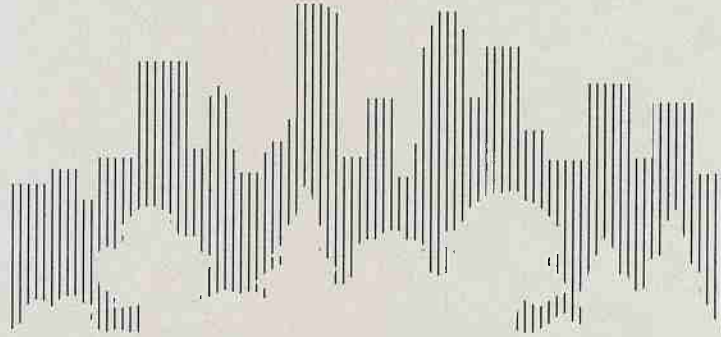
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## MASTERS IN SOCIAL WORK THESIS

**Karen S. Cartwright**

**The Utilization of Hospice Care  
in Assisting to Meet the Needs of Family Members  
of Terminally Ill Patients**

**MSW  
Thesis**

Thesis  
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1997

The Utilization of Hospice Care in Assisting To Meet  
The Needs of Family Members of Terminally Ill Patients

by

Karen S. Cartwright

A Thesis

Submitted to the Graduate Faculty

of

Augsburg College

in Partial Fulfillment of the Requirements

for the Degree

Master of Social Work

Minneapolis, Minnesota

May, 1997

MASTER OF SOCIAL WORK  
AUGSBURG COLLEGE  
MINNEAPOLIS, MINNESOTA

CERTIFICATE OF APPROVAL

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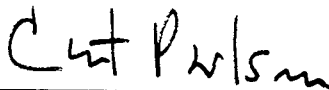
has been approved by the Examining Committee for the thesis requirements for the Master of Social Work Degree.

Date of Oral Presentation: May 14, 1997

Thesis Committee:



Thesis Advisor (Sharon K. Patten, Ph.D.)



Thesis Reader (Curt Paulsen, Ph.D.)



Thesis Reader (Carol O'Brien, LICSW)

## I'M FREE

Don't grieve for me, for now I'm free  
I'm following that path God laid for me.  
I took His hand when I heard Him call  
I turned my back and left it all.  
I could not stay another day  
To laugh, to love, to work or play.  
Tasks left undone must stay that way.  
I found that peace at close of day.  
If my parting has left a void,  
Then fill it with remembered joy.  
A friendship shared, a laugh, a kiss,  
Ah yes, these things I too will miss.  
Be not burdened with times of sorrow  
I wish you the sunshine of tomorrow.  
My life's been full, I've savored much.  
Good friends, good times, a loved one's touch.  
Perhaps my time seemed all too brief  
Don't lengthen it now with undue grief.  
Lift up your hearts and share with me  
God wanted me now; He set me free.

Author Unknown

To my husband, David,  
whose support, patience, and  
computer knowledge  
made this possible.

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Thank you to my supervisor and friend, Carol, and coworker, Karla, for their constant encouragement, flexibility, understanding when I was "not so pleasant", and for always believing I would complete this, even when I was not so sure. Thank you also to my classmates, especially Suzy, for their friendship and making this whole process worthwhile.

I want to thank my friends and family for their understanding and support, and for allowing me to disappear for awhile. Especially to my parents, who instilled in me the desire to obtain a higher education and be successful, and who have supported me through every rough road I have encountered in my life, and for whom I have the utmost respect and love.

## **ABSTRACT**

### **THE UTILIZATION OF HOSPICE CARE IN ASSISTING TO MEET THE NEEDS OF FAMILY MEMBERS OF TERMINALLY ILL PATIENTS**

EXPLORATORY RESEARCH STUDY

KAREN S. CARTWRIGHT

MAY, 1997

The diagnosis of a terminal illness greatly impacts the patient as well as the entire family system. The relevant literature mentions the concept that hospice can be beneficial to families by assisting them in meeting needs and providing support and guidance. Little research, however, has been done to support these beliefs.

The purpose of this research study was to explore what benefits hospice provides to family members of terminally ill patients. A questionnaire was mailed to 128 primary care persons of patients who were enrolled in the hospice program and died between February 1, 1996 and July 31, 1996. A 64% response rate was obtained. The findings suggest that family members felt the services of hospice care benefited them, and even a slight majority felt the hospice team helped to make their bereavement process easier. These findings support the use of hospice care for terminally ill patients and their families, and more research is needed to strengthen this support.



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## **I. Introduction**

### **A. Overview of Hospice**

The demographic profile of the United States in the twentieth century is that of an “aging society”. Mortality and fertility rates have declined, and most people survive their childhood and middle years to die in old age (Fulton & Bendiksen, 1994). How people die and what they die from has also changed over the twentieth century. In the early 1900s, most people died from infectious diseases, such as influenza, pneumonia and tuberculosis. These deaths occurred quickly and suddenly. People were not generally subjected to chronic illnesses.

Gradually, and “as a result of public health measures, improved nutrition, institution of occupational health standards and the pharmacologic advances of the twenties and thirties, infectious disease yielded to heart disease, cancer and other chronic disorders as the major cause of death” (Fulton & Bendiksen, 1994, p. 365). This created new demands and stresses affecting terminally ill patients and their families, as people started living longer, and dying longer. When the diagnosis of a terminal illness occurs, individuals enter a new phase of living that can last several months and even years. Chronically, terminally ill people require extensive treatment, care and support which place unique burdens on family members. The development of the hospice movement was in response to the changing needs of an aging society and as a means to establish a humane way of caring for terminally ill patients. A way of caring that emphasizes palliative versus curative treatment, so that patients may die with dignity, their pain managed and their families present (Davidson, 1985; Fulton & Bendiksen, 1994; McCann, 1985; Munley, 1983; Torrens, 1985).

Along with the changes in the most prevalent illnesses taking people's lives over the twentieth century came advancements in medicine. Medical technology also contributes to people living longer with terminal illnesses. Modern medicine has made remarkable gains in prolonging and saving people's lives. Yet, for some people there comes a time when nothing more can be done medically to prolong their lives. This is when hospice care becomes a viable option for many terminally ill patients.

With the advancement in technology and the availability of home care, more and more terminally ill patients choose to die at home. However, this requires a family member or a close friend who will assume the responsibility of caring for the patient at home. To assist with this responsibility, the use of hospice care has been growing and expanding over the past several years as a way to help keep these patients in their homes as long as possible.

The most common misconception about hospice is that it represents a place. Hospice is a form and philosophy of care that emphasizes palliative treatment and the involvement of family members. It requires a physician's order and is offered to patients who are terminally ill and have a life expectancy of six months or less, and who no longer want any extraordinary measures taken to prolong their lives. Hospice care can be provided in a variety of settings, including patients' homes, hospitals, residential settings and long-term care facilities. The most common setting is the patient's home, which usually requires a primary care person available to care for the patient. Not everyone is able or wishes to die at home. They do, however, receive continuity of care within the hospice program and philosophy, regardless of the location of care.

Hospice care is unique and desirable in that it provides services that conventional care does not deliver. These services include: a nurse on-call 24 hours a day to assist the family in caring for its loved one, home health aides to assist with bathing and caring for the patient at home, medical social services to provide grief counseling and help with financial concerns, spiritual care providers, and trained volunteers who can offer respite to the family and an opportunity to get out of the home (Kastenbaum, 1995; Kirschling, 1989; Kulys & Davis, 1986; MacDonald, 1991; McCracken & Gerdson, 1991). One of the most unique characteristics of hospice is the focus it provides on the family as part of the unit of care along with the patient. The health and well-being of the family are important and hospice offers services to assist the family in caring for its loved one. Hospice also focuses on the grief and bereavement of families and offers grief counseling and bereavement follow-up for one year after the death has occurred, and longer if necessary.

### **B. Purpose of the Research Study**

The diagnosis of a terminal illness greatly impacts the entire family system along with the patient, which makes the emphasis of hospice on the care of both so appealing and imperative. A terminal illness can inflict people of all ages. This research study, however, focuses on terminal illness among adults. The terminal illness can affect the entire family by disrupting roles and requiring role reversals, shattering future plans and goals, depleting financial resources and permanently changing and requiring adjustments in lifestyle of all members of the family (Schachter, 1992; Vachon, Kristjanson & Higginson, 1995). Suszycki, Abramson, Prichard, Kutscher, and Fisher (1984) compare the family to a mobile and how a terminal illness upsets the equilibrium and has

immediate and long lasting effects. Each member is connected by a single strand, and each can move and change independently to a certain extent, but each movement will ultimately affect every other member and the whole. During the course of a terminal illness, care is commonly assumed by one family member, most typically a spouse or a child. This can often be a long and strenuous process for the family as well as the patient.

The purpose of this research study consists of exploring the needs of family members of patients with a terminal illness and attempts to explore how the use of hospice care can benefit them. Research has demonstrated the significance of hospice care as families voice greater satisfaction with care provided to their terminally ill members by a hospice program than any other form of care (Dawson, 1991; Seale, 1991). A significant amount of research has been done to identify the needs of family members of terminally ill patients. A critical aspect of hospice care is the assistance it provides family members with their grief and bereavement processes. Only a scarce amount of research has been done regarding the concept that early grief work can be facilitated through the hospice team, prior to the actual death, which can help ease the bereavement process for families of terminally ill patients. The intention of this research project is to build on this relatively new evidence on grief work, and to strengthen the support for the use of hospice care for terminally ill patients and their families by identifying how hospice care can benefit them.



### **C. Research Questions**

This research study addresses the following research questions:

What are the needs of family members of terminally ill patients?

What benefits can hospice care provide the family members of terminally ill patients?

Is hospice care effective in easing the bereavement process of family members of terminally ill patients?

The needs of family members were identified through the literature review. These needs were formed into statements and participants completing the self-administered questionnaire were asked to rate how beneficial they feel hospice was in assisting to meet those needs. Some questions on the self-administered questionnaire focus on the grief and bereavement of the families to discover if they feel hospice has assisted them through some of their grieving process.

### **D. Significance for Practice**

This research study is an in-depth exploration of hospice care and the impact of a terminal illness on families. If it is found that hospice benefits families and assists in making the bereavement process easier, this study can help expand the theory and knowledge base on grief and death and dying issues. It can provide support for the use of hospice care for terminally ill patients and identify key needs of families and helpful information for grief counselors. If indeed hospice is determined beneficial, its use should become more prevalent with terminally ill patients and their families.

## **II. Literature Review**

### **A. Historical Background and Growth**

Dame Cicely Saunders is considered to be the originator of the modern hospice concept, as she was the founder of the first pioneering St. Christopher's Hospice in London in the late 1960s (Dawson, 1991; Kulys & Davis, 1986; McCann, 1985; Munley, 1983; Torrens, 1985). Trained as a nurse, medical social worker and a physician throughout her career, Saunders had a mission to create a model program that would teach the management of terminal disease (Weir, 1989), focus on controlling and relieving the pain and suffering of the patients (Davidson, 1985; Munley, 1983; Torrens, 1985), and also use a multidisciplinary team to meet all of the physical needs of the patients as well as the psychosocial needs of both patients and their families (Dawson, 1991; Kulys & Davis, 1986).

After visitors from the United States observed the effectiveness of St. Christopher's Hospice and examined the philosophy at work, hospice began to develop in the United States. The first of its kind opened in 1974 in New Haven, Connecticut (Richman, 1990). It opened with a home care program and a forty-four bed inpatient facility. Later, in 1975, an international task force convened to further develop standards of care for terminally ill patients and discuss issues on death and dying (Kastenbaum, 1995). Mor, Greer, and Kastenbaum (1988) describe the two very basic guidelines proposed by the task force as "(1) the terminally ill person's own preferences and life-style must be taken into account in all decision making; and (2) family members and other caregivers also have legitimate needs and interests that must be taken into consideration" (p. 9). This International Work Group on Death and Dying included

Dame Cicely Saunders and other pioneers. They developed guidelines to stimulate the growth of hospice care (Kastenbaum, 1995).

A major research study, the National Hospice Study (NHS) was conducted from 1978 to 1985. This was the first major review of hospice to determine the effectiveness and success of the hospice mission in the United States. The NHS was established to determine how closely hospice care functions according to its own philosophy and whether it attains its stated goals. It was also designed to assess if it is indeed superior to conventional care, and, if so, how. The study used a sample of forty hospital-based and home-based hospices. It essentially compared patients served in these settings with those terminal cancer patients receiving care from a variety of non-hospice, conventional care settings (Mor, Greer, & Kastenbaum, 1988). The study basically revealed that the hospice experiment in the United States appears to be working. Mor, Greer, and Kastenbaum (1988) describe the NHS in great detail in their book, The Hospice Experiment, and they state that essentially, “hospice care has some positive and no negative effects on cancer patients in their last weeks of life when compared with conventional medical care” (p. 109-110).

The hospice movement has grown steadily since coming to the United States in the early 1970s. The National Hospice Organization (NHO) reported that there were approximately 50 hospice programs in 1977 (Lerman & Tehan, 1995). In 1982, there were an estimated 800 hospices serving 50,000 patients (Eisdorfer, Kessler, & Spector, 1989). By 1986, it had grown to approximately 1,400 hospices serving 100,000 patients (Weir, 1989), and the estimate had grown to 2,000 hospice programs in 1994 (Kastenbaum, 1995; Lerman & Tehan, 1995). The hospice movement grew out of a need

to deal effectively with people's pain and assist families with their grief, and it continues to grow today.

### **B. Effects of a Terminal Illness on Family Members**

Much of the literature surrounding the diagnosis of a terminal illness includes the impact the terminal illness has on family members. The expansion of home hospice programs across the United States enables people facing a terminal illness to choose to die at home if they so desire and if there is a family member or close friend who will assume the responsibility of that care. The term 'family' will be used liberally in this paper to include anyone the terminally ill patients choose to have involved in their care. McCracken and Gerdson (1991) define family as it relates to terminal illness "in an expansive sense to include any relative or individual who has significant personal ties to the individual" (p. 5). Terminally ill patients are cared for and die in a variety of settings and despite the location of care, the family can experience severe stress.

#### Terminal Cancer

Schachter (1992) emphasizes that the decision to be cared for at home must be agreed upon by family members who will be intimately involved in that care and who will also face challenging burdens and demands. Schachter studied the quality of life for family members who are the primary caregivers for cancer patients who choose to die at home. She identified several key factors that impact their quality of life. Role reversal occurs for some as the cancer progresses and previous roles, which may have been the foundation of the family's structure, often crumble. These changes can cause conflict and marital disarray (Schachter, 1992). Other key factors found by Schachter that impact the quality of life for family members include: the lack of knowledge and skills needed

to perform complicated procedures as the patient's condition deteriorates; the lack of privacy as home care staff are frequently present; the physical exhaustion and demands of care that were not fully anticipated or realized when they agreed to care for the patient at home; the psychological stressors of dealing with the changing physical and mental condition of the patient, and also the financial burdens placed on them as a terminal illness often depletes one's finances and savings. Schachter believes it is imperative for all staff working with cancer patients and their families to be aware of these major stressors involved in the caregiving process. She identifies several critical needs that families will experience in the care of their terminally ill members at home, however, she does not expand on how home care staff can better assist in meeting those needs.

Several other studies reveal further needs of family members of terminally ill patients and confirm those mentioned above. Families can have a variety of needs during a loved one's illness and if those needs go unmet, stress escalates and impedes upon the family's ability to function effectively (Kristjanson, 1989). Four main concerns of families identified by Kristjanson through a review of the literature include: problems created by symptoms of the disease, fear of the future, waiting, and difficulty obtaining information. She found that families need assistance with the physical care of the patients, need access to information, and also need a place where they can discuss their fears.

McWhinney (1989) focuses on the need for interaction between the cancer care system and the family system to promote the quality of the patient's care. He stresses the importance of communication and the need to completely inform families. Problems arise when patients and families are given too much information at once or feel they have

been given conflicting information from different people. Other factors that add stress for caregivers are the fear of “doing the right thing” as they are responsible for assessing pain and administering medications, and they often lack sleep. McWhinney provides some tips for intervention, clarifying that knowing the different coping styles of families can enable professionals to help them through the coping process. A self-sufficient family may react poorly to the assistance of outside support and a dysfunctional family is not likely to resolve their problems when a member becomes terminally ill (McWhinney, 1989). He concludes that, “helping families to resolve their conflicts is an important aspect of palliative care and the presence of a Social Worker and Pastoral Care Worker are great assets” (p. 38). Since this article was written in 1989, this writer believes the role of the social worker in terminal care has developed and become more prominent and is more than a “great asset”. However, it still needs to be clearly defined and integrated.

The research cited above discusses terminal cancer and points out the importance of providing family caregivers with the information and knowledge needed to care for their patients in an effort to prevent anxiety. The authors varied in their reports of other factors contributing to the stress of families. This writer finds the information provided by Schachter (1992) to be the most complete and descriptive, however, combining them provides a very useful tool in discovering the effects of terminal cancer on families.

### End-Stage Lung Disease

Patients and families dealing with end-stage lung disease (ELSD) share similar burdens with cancer patients and families but also have some unique characteristics. Kinzel (1992) describes this disease as a fatal condition which places a substantial amount of suffering on its patients. The patient is generally ill for many years prior to

reaching end-stage lung disease and once the disease is diagnosed, the symptoms slowly progress. One common and quite dramatic symptom in end-stage lung disease patients is panic, which is related to severe shortness of breath and requires immediate treatment. This can cause pronounced panic and fear in families who are caring for patients with this disease. Kinzel (1992) contrasts it with the hospice care normally received by cancer patients as “in ESLD, the decreased ability to prognosticate, the frequently prolonged course of disability, and the decreased efficacy and increased invasiveness of symptom control create caregiving burdens not traditionally seen in hospice” (p. 139).

### Alzheimer’s Disease and Dementia

Caregivers for people with Alzheimer’s disease and other related dementia definitely face some unique challenges than those caring for people with other terminal illnesses. In addition to assuming complete responsibility for the patients’ personal, financial and health care matters, these caregivers endure even more painful stressors. These stressors include: watching these patients slowly lose their cognitive functions until they do not even recognize these caregivers as family members; noticing how their personality and intellectual traits that make them unique individuals dwindle away; attempting to manage the sometimes belligerent, suspicious, hostile and aggressive behaviors of these patients; and enduring lengthy and costly care which almost always leads to institutionalization as these patients require round-the-clock care and constant supervision (Austrom & Hendrie, 1992). Strained physical health due to physical and emotional exhaustion, a sense of abandonment and isolation from family and friends, marital strain and feelings of guilt if nursing home care becomes necessary are also some

effects on caregivers taking care of this most challenging population (Austrom & Hendrie, 1992).

Zweibel and Cassel (1989) and Sonnenblick, Friedlander and Steinberg (1993) address the issue of decision-making regarding appropriate health care for people with Alzheimer's disease and other related dementia. Many decisions about aggressive treatment and life-sustaining measures need to be made and, unless the patients completed a Health Care Declaration or Living Will prior to becoming incapacitated, the caregivers are responsible for making these decisions. Another unique challenge faced by caregivers of people with Alzheimer's and other forms of dementia involves the feasibility of palliative and respite care for these patients. People with these diseases make ideal candidates for hospice care as their prognosis is poor, aggressive medical treatment is usually not recommended or pursued, and they suffer from other medical complications associated with the disease. However, access to hospice programs for patients with Alzheimer's disease and related dementia disorders is minimal, particularly due to the uncertain survival time for these patients (Hanrahan & Luchins, 1995). This impedes on the ability of caregivers to obtain assistance in the care of their loved ones. Certainly, increased awareness of this need along with the development of specified criteria and guidelines for the enrollment of these patients into hospice care is needed (Hanrahan & Luchins, 1995).

Health care professionals can assist the caregivers of patients with Alzheimer's or other forms of dementia. They need to be cognizant that the caregivers themselves require time to discuss their concerns, especially their feelings of anxiety, exhaustion and depression. Health care professionals can help the caregivers to understand that these



feelings are common and that they may also uncover some feelings of anger and resentment towards the patients (Austrom & Hendrie, 1992). The professionals among hospice care staff can assist the caregivers in additional ways, including respite care, bereavement counseling and assistance from home health aides, which could help to alleviate some of the strain on caregivers (Luchins & Hanrahan, 1993). A common theme in this research is the need for strong social support to assist these caregivers with their increased burdens.

### AIDS

As the number of people with AIDS continues to grow across the United States, the need for increased home care and hospice programs for this population also grows. This is a unique, challenging and misunderstood population of ill people, in which much education and training for professionals is required. Folkman, Chesney, Collette, Boccellari and Cooke (1996) provide an inclusive description of a new group of bereaved caregivers the AIDS epidemic is creating as “gay men who are in early middle age and in primary relationships that are not legally recognized and whose partners have had an illness that is stigmatized and with which the caregivers may themselves be contending” (p. 343). This poses immense challenges for these caregivers, and increased awareness and knowledge is necessary for professionals who assist in that care.

People with AIDS and their caregivers have multiple and complex psychological concerns that vary dependent upon their own coping mechanisms and the support they receive from family, friends and the community. Some issues they face include: a lack of financial resources, the lack of traditional support systems from which they may be alienated due to the nature of their disease, loss of housing due to financial strains and

lack of outside assistance, and the loss of control over legal matters. People with AIDS and their caregivers may also be coping with multiple losses, as others close to them in the gay community may have died from this illness (Martin, 1988).

The professional staff assisting in the care of AIDS patients must be cognizant of their unique situation as these patients have multiple physical and psychosocial problems which are more intense than those of most traditional hospice patients (Martin, 1986). Jimenez and Jimenez (1990) establish a critical point to be aware of with AIDS patients as they are likely to maintain a more hopeful attitude and outlook longer than the traditional patients who receive hospice care. This can be due to the unpredictability of the disease and the idea that new drugs may be discovered to prolong their lives at any time. Given this positive outlook and the young age of many of these patients, denial is not uncommon among them (Jimenez & Jimenez, 1990). It is imperative that health care professionals be aware of this and not pressure these patients into discussing their illness and impending death. Being supportive and accepting of their “adaptive denial” is critical.

Specified training and education on the AIDS virus itself is essential for anyone working with this population. A multidisciplinary team approach is most helpful for this population given the complexities of the disease. Hospice programs can be beneficial not only because they provide the team approach, but also due to the sensitive and humane approach they generally provide to their patients (Martin, 1986). There is little literature surrounding AIDS and hospice care and it may be another underserved population. However, due to the young age of many of these patients, they frequently seek aggressive

treatment until the end of their illness rather than enroll in hospice, which emphasizes only palliative treatment.

### Ethnic Minority Patients

Terminally ill ethnic minority patients represent another underserved population in the health care industry. Family members of these patients face additional barriers and difficulties to obtaining care for their loved one. One difficulty that can limit their understanding of available options is language barriers (Gordon, 1995; Noggle, 1995). Family caregivers, who are typically of the younger generation, often become interpreters, which only adds to their responsibilities. If communication is a problem, it can often lead to a lack of trust in the health care professional (Gordon, 1995; Noggle, 1995). Other barriers for ethnic minority patients and families cited by Gordon (1995) include: the lack of an available primary caregiver within the family as the need to work is greater, lack of financial resources, and the lack of good health insurance which can limit their access to a physician who would refer them to the available health care.

Cultural differences include variances in the view of death and dying issues, which can also lead to miscommunication and misunderstanding. The issue of death and dying from a Native American perspective is explored by Halfe (1989), who describes the circle of life and death with which native people are raised and taught. Halfe clarifies the myth that native people are more accepting of death and states, “death is not welcomed with open arms, but is rather viewed as a reality of life. Life must continue its circle to death and even after death to life again” (p. 40). She also discusses the factors of social isolation, lack of education in health awareness, high cost, and language and

cultural barriers that make it more difficult for natives, especially elderly natives, to deal with a terminal illness.

Ethnic elderly who are in long-term care facilities also face unique difficulties, which can complicate their care. MacLean and Sakadakis (1989) point out that ethnic minorities grow old in a “second homeland” and experience the natural physical and social stresses of aging, which are “compounded by the actual difficulty of coping with personal and cultural age-related changes in a country different from that of their birth in which their earlier socialization of being old may not apply” (p. 209). The relationship between the ethnic elderly population and health care systems tends to be stressful for both groups due to sociocultural differences and inexperience of dealing with each other. MacLean and Sakadakis (1989) also discuss interventions of treatment planning, advocacy, and supportive therapy used in ethnic elderly people in long-term care to assist in providing high quality care. These authors provide excellent suggestions with supporting case studies for social workers in long-term care working with ethnic minorities, which is quite significant given that there is not a large amount of literature on the subject.

There are other suggestions the literature provides for health care professionals to assist them in working with ethnic minority patients. They need to look beyond their own culture and seek education on the cultures with which they are working, and one powerful way of doing this is to ask someone within that culture to explain how they understand and experience things (Irish, Lundquist, & Nelson, 1993). It can be helpful to learn their terms and use them properly. It is important to be cognizant of how they may view interventions. For example, some minority families may view the members of a

hospice team coming to their home to assist them as intruding on their privacy, as it can violate a cultural norm (Noggle, 1995). They may fear that hospice will come in and try to take over and change things, which can be threatening for them. Education on cultural diversity is the key for hospice staff and all health care professionals in order to be able to provide the best possible care.

### **C. Anticipatory Grief and Bereavement**

Norris and Murrell (1987) define anticipatory grief in their article as “the condition in which one is so concerned about the threat of an approaching loss that he or she experiences the grief reaction before the loss occurs” (p. 607). Chronic, terminal illnesses may cause anticipatory grief, especially the dementing illnesses where the patients slowly lose those traits that made them unique individuals. Vachon, Kristjanson and Higginson (1995) report some effects of terminal illness on family members, stating, “the burden of illness is borne by family members who may also experience distress and poor health, financial problems, and disruption in their work lives” (p. 142). Kirschling (1989) and Knapp and Delcampo (1995) agree that the strain of caring for a dying person can hinder the emotional and physical health of each member of the family. However, Norris and Murrell (1987) report findings that state grief and bereavement do not affect health or cause poor health among family members. Vachon, Kristjanson and Higginson (1995) further describe four major dimensions of the experience of terminal cancer in families, which include the developmental stage of the family, cancer illness trajectory, meaning the various stages of the illness, family responses to cancer - how much role changing is required and whether or not they have good communication - and health care

provider behaviors important to family care, which again stresses the need for information from the health professionals.

Berardo and Berardo (1992) agree that the developmental stages of families affect their adjustment to terminal illness. They state that family life stages of patients and their family caregivers are related and connected to their psychosocial adjustment problems. They detail the various stages and how families may react to a terminal illness in each stage. Although the articles focus on many different experiences of family members, and they do not all agree on certain effects on families, they do all support that families are greatly impacted by the terminal illness in a member of their family. Many articles suggest interventions for health professionals working with terminally ill people and their families.

Bereavement is defined as the psychological, physiological and behavioral responses to a loss (McNeil, 1995). The term can encompass the entire process experienced by people after suffering a loss. The term grief describes the intense feeling or emotional pain felt as a result of a loss (McNeil, 1995). Huber and Gibson (1990) suggest that people can gain some control over their grief by “learning to (1) accept the reality of the death, (2) experience the pain of grief, (3) adjust their environments, and (4) reinvest emotional energies into getting on with the rest of their lives” (p. 52). This is a difficult process and can be facilitated with the assistance of health professionals. Norris and Murrell (1987) also suggest that interventions after the loss may be too late, as family caregivers may be a more relevant target than individuals in bereavement for interventions designed to promote good health or to alleviate stress. The involvement of

practitioners becomes increasingly more relevant as the elderly population continues to grow along with the need for family members to become caregivers.

#### **D. The Role of the Social Worker in Terminal Care**

##### Assisting Families

Family members experience a variety of reactions to the diagnosis of a terminal illness, including guilt, resentment, fear, withdrawal, and anxiety. Assistance in coping with these feelings is imperative because some research indicates that the mood of the family members caring for an ill member can have a compelling, profound effect on the patient's own emotional adjustment to his/her impending death (Guilfoyle, 1992). Social workers can assist families in dealing with these emotions by promoting expression of feelings, and by being willing and able to discuss death openly themselves (Guilfoyle, 1992). They need to first deal with their own emotional responses to loss and death in order to provide effective treatment (van Wormer, 1990). Social workers can help families understand that their feelings are normal and to help them learn the source of their feelings.

Social workers can also assist patients in working through some of their own emotions by providing a sympathetic ear and encouraging them to express their feelings so they can resolve any anger or regret they may feel and find peace (Bissell, 1992). The social worker assisting persons with AIDS often intervenes with housing concerns, financial difficulties, emotional support, planning funeral arrangements, and bereavement follow-up (Martin, 1988). The social worker often becomes intimately involved with this population as they face unique issues, such as the lack of financial resources, multiple loss and often conflict within the family. The social worker assists in

identifying resources for the patients, friends and families to help them resolve this conflict (Martin, 1988). Social workers assisting hospice patients and their families may follow this model: anticipate and identify the needs of the terminally ill patients and their families, follow the patients and those significantly involved through a caring process, and then determine and take action against barriers in the environment which may be preventing a safe passage for the patients (Rusnack, Schaefer & Moxley, 1991).

#### The Lack of a Clearly Defined Role

Remsen (1993) explores the issue that the role of the social worker in terminal care has not been clearly established. She studied the role of the nursing home social worker in terminal care and found that the majority of social workers reported that the topic had not been discussed in their facility. Further research also suggests that social workers do not play a unique role and lack involvement in hospice programs for terminally ill patients (Kulys and Davis, 1986; MacDonald, 1991). However, Kulys and Davis identify key tasks which social workers should be involved in, including: developing and implementing staff support programs, assessing the psychosocial needs of patients and families, providing direct services to patients and families, and providing bereavement counseling. Other social work activities in hospice care include: referral, problem-solving, brokerage, case management, crisis intervention, client advocacy, and assisting patients and families with the financial and social implications of dealing with a terminal illness (MacDonald, 1991).

#### Social Work Practice with the Terminally Ill

The importance of support groups in working with terminally ill patients and their families is also mentioned in the literature. The combination of both patients and



families in the same support group “provided a broader network of support and helped to avoid the tendency to make illness a socially isolated event” (Duhatschek-Krause, 1989, p. 59). Group work is done by hospice teams not only to serve the needs of their patients and families, but also to meet the needs of the staff as well. Hospice staff continually face the death of their patients and experience a high level of stress in their jobs. The use of social support groups for the staff has been shown to be effective in combating some of those stresses (Richman, 1990). Also supported throughout the literature is the idea that the involvement of hospice care programs can effectively assist families and patients in dealing with the stressors involved in coping with a terminal illness.

### **E. The Role of Hospice Care**

#### The Needs of Family Members

The review of the literature identifying the effects of a terminal illness on family members reveals several key needs of these families. Those who decide to care for their terminally ill member at home need support from the hospice team in their decision and also much assistance. A critical need of family caregivers is knowledge (Schachter, 1992). It is imperative that health care professionals explain explicitly all needs and cares required by the patients. Families need instructions to develop skills necessary to care for these patients, including skills in the area of pain management, respiratory comfort, nutritional needs, skin and wound care, and bladder and bowel management (Schachter, 1992).

A related element for family caregivers is to maintain a sense of control and receive assistance from health care professionals in managing the patients’ cares (Austrom & Hendrie, 1992). This is to avoid feelings of helplessness and abandonment

in caregivers, as they need much support. Families also benefit from consistent, reliable information from all of their health care providers (Kristjanson, 1989; McWhinney, 1989). Families often need increased in-home assistance from the hospice team as a frequent problem is a limited support system not previously anticipated which resulted in a lack of relief and assistance needed by family caregivers (Etten and Kosberg, 1989). Other documented needs include an opportunity to discuss their personal feelings and fears (Etten and Kosberg, 1989; Kristjanson, 1989), emotional support, and assistance in getting medical equipment (Kristjanson, 1989).

### Support for Hospice Care

Literature on hospice care is just beginning to recognize its success in providing care with the unique focus of the family as part of the unit of care along with the patient. Families involved in caring for the dying patients can provide loving care and attention which may prevent or alleviate some of the pain of loneliness felt by the patients (Magno, 1990; Rosen, 1987). Involving families in the care enables the family members to come to terms with the reality of the impending death (Huber and Gibson, 1990). Whereas Magno focuses on the benefit of involving families for the patients, Huber and Gibson contend that it also benefits the families.

McCracken and Gerdson (1991) provide an excellent overview of the physical, psychological and emotional issues in both patients and families dealing with terminal illnesses. They promote hospice care as beneficial in providing respite care through home health aides and volunteers for those families caring for patients in their homes. Also, the availability of social workers to assist families in addressing grief and loss issues, assessing emotional needs, and working with financial concerns and family

disagreements provides another advantage of receiving hospice care during this most difficult time (McCracken & Gerdson, 1991).

The unique opportunity the hospice staff has to observe, support, educate and monitor families facing the loss of a loved one allows for special attention and assistance to be given to them during their bereavement process (Gardner, 1985). Many hospice programs offer bereavement follow-up to families for up to a year after the death. The systematic assessment of the needs of the caregivers along with plans for assistance for these caregivers should be a primary focus of all hospice programs everywhere (Etten & Kosberg, 1989).

#### Significance of Hospice

Research on hospice care is also beginning to demonstrate its significance. Little research has been done to compare the receipt of hospice care to that of conventional care. However, research that has been done supports the use of hospice care.

Kastenbaum (1995) and Munley (1983) delineate many case examples from across the United States which support that patients and their families do benefit significantly from the use of hospice services. Kramer (1992) studied the differences between widows whose spouse received hospice care before their death with those who did not. She found that the women who received hospice involvement experienced less grief both before and after the death. Kramer suggests that the hospice philosophy of attempting to meet the emotional needs of familial caregivers is beneficial in easing their grieving process.

Luchins and Hanrahan (1993) mention research that suggests family caregivers receiving hospice services experience less anxiety than those receiving conventional

care. Dawson (1991) and Seale (1991) both present research that indicates the significance of hospice care as their studies found that families voice greater satisfaction with care provided to their terminally ill member by a hospice program than any other form of care. More research needs to be done in this area in order to provide further support for the significance of hospice care and to promote its increased use across the United States.

### Hospice Care Settings

Although the most common setting where hospice care is provided is in the patients' homes, other settings also exist. Hospice care can also be provided within hospitals and long-term care facilities. Another site for care is extremely new and not fully recognized. Hospice homes are large residential homes converted into places that provide care for terminally ill patients. They offer private rooms and around-the-clock care and are just beginning to open and become recognized. In-patient hospice units at hospitals are most typically used for acute symptom management, to provide respite for family caregivers, and in the final days of an illness when the patients and families have chosen not to die in their homes.

Infeld, Crum and Koshuta (1991) explore the idea of hospice care in the long-term care setting. They studied the characteristics of some hospice patients treated in a long-term care facility and found some trends, including a decreasing length of stay, growing participation by HMOs, increasing diagnoses other than cancer including AIDS, and decreased hospital referrals (Infeld, Crum & Koshuta, 1991). They propose that nursing home-based hospice care may be under-utilized and is economically more efficient. They feel long-term care based hospice settings will meet a growing need in

the future as older patients will increasingly encounter the lack of an available caretaker in the home (Infeld, Crum & Koshuta, 1991).

Schachter (1992) focuses on care in the patients' homes, emphasizing that even though it places added stress on family members and alters their routine, "dying at home provided greater cohesion and less disruption than hospital death, possibly making the bereavement process less difficult, and thus enhancing the quality of life" (p. 66). Kaye and Davitt (1995) state some advantages of providing care in the homes, including: the presence of family and familiar surroundings, less expense, less danger of contracting an infection, and greater opportunity to participate and be active in family life. Much of the literature supports that, whether the care is provided in a hospital, the patient's home or a long-term care setting, hospice care is beneficial in meeting the physical needs of patients and can also be successful in alleviating some of the strain and burdens placed on family members.

#### **F. Gaps in Literature Review**

This author found a considerable amount of research on the terminal illnesses of cancer, Alzheimer's disease, and other dementia-related diseases. Many needs of family members were identified by this population. Only one article was found on end-stage lung disease (ESLD). This is not as common a disease as those previously mentioned, and it is not as well-known. Also, related diseases for which people seek hospice care include: Congested Heart Failure (CHF) and Chronic Obstructive Pulmonary Disease (COPD). Research articles specific to these diseases were not found by this author. However, these diseases are considered more chronic than terminal and it is very difficult to determine when patients have reached the final, terminal stage of these illnesses,

which can explain the lack of research regarding the use of hospice care for these particular illnesses. It is the experience of this author that the use of hospice care for patients with CHF and COPD has just recently become recognized as a viable option for these patients.

Little research was found during an initial search on ethnic minority patients. However, considerably more articles were found in a more extensive search. Surprising to this author, only four articles related to the purpose of this study were found on AIDS. Two of those four articles were not very recent and were written in the mid-1980s. Quite possibly, the needs of family members of patients with AIDS have not been fully addressed or acknowledged. This disease contains some very unique and complicated issues surrounding the family system with significant other members, including partners, involved. Given the relative newness of this disease, along with these complicating issues, this is an area of study that needs much more extensive research.

### **G. Conclusion**

The diagnosis of a terminal illness can have a variety of effects on the entire family system, as shown through this literature review. The effects can be unique to the illness - whether it be end-stage dementia, Alzheimer's disease, end-stage lung disease, terminal cancer or AIDS - and can also be different depending on the setting - hospitals, long-term care facilities, or the patients' homes. However, the impact is significant and must be addressed in order to assist family members in supporting and caring for the dying patient. More research is needed in the area of comparing the receipt of hospice care versus conventional care to determine and hopefully strengthen its significance. However, extensive research has been done acknowledging the severe effects of a

terminal illness on family members, which have been outlined throughout this literature review. This author supports the concept of hospice care and believes that wherever hospice care is provided, it can reduce the family stress resulting from a terminal illness. The development of a terminal illness in a family member is a traumatic stressor for all those involved. It is an uncertainty that generates fear, anxiety and many questions in those afflicted. Hospice can provide the care needed to meet the physical, emotional and spiritual needs along with providing imperative information, support, and bereavement counseling which can all lead to more effective coping skills in patients and their families.

### **III. Theoretical Framework**

#### **A. Grief Work Theory**

Having a clear understanding of the theoretical perspective on grief can be extremely useful in efforts to help survivors cope with the loss of their loved ones. It can enable professionals to make more astute observations and better understand the responses of the grievors to their loss (Kastenbaum, 1995).

Sigmund Freud first introduced the concept of “grief work” theory and it was in response to the mass death and bereavement of World War I (Kastenbaum, 1995; Freese, 1977). Freud developed the following basic beliefs of grief work: grief is an adaptive response to loss; grief work is time consuming and difficult; the primary goal of grief work is to accept the reality of the death and free oneself from the attachment to the loss; the work of grief is done through a long series of confrontations with the reality of the loss; it is complicated by the survivor’s reluctance to let go of the attachment to the loss; and when the grief work is not completed, the result is continued misery and dysfunction (Kastenbaum, 1995).

Freud concentrated on people’s responses to their losses and focused on how they dealt with their thoughts and feelings. Later contributors to the grief work theory, such as John Bowlby and Colin Murray Parkes, focused on how suffering a loss affects relationships with other people (Kastenbaum, 1995). The following four tasks of grief work were also later developed as the theory progressed: accepting that the loss is a reality; entering into the emotions of grief; acquiring new skills; and reinvesting energy in new ways (Leick & Davidsen-Neilsen, 1991).



## **B. Theories on Death and Dying**

The development of hospice care has in part stemmed from the efforts of Elisabeth Kubler-Ross on death and dying issues. Her focus on people's reactions to the prospect of losing their lives began a movement of assisting families with the dying process, and realizing that the dying patients themselves need to talk about their situation. Kubler-Ross developed a model of five stages of grief people experience when they discover they have a terminal illness. The stages include: denial, anger, bargaining, depression, and finally acceptance (Katz & Sidell, 1994; McNeil, 1995; Torrens, 1985). However, this model can be viewed too rigidly as not everyone will follow these stages in that exact order and some people may never reach the final stage of accepting their death.

John Bowlby first used the term 'separation anxiety' to describe feelings people experience when they lose something or someone close to them or to which they feel attached (Katz & Sidell, 1994). Peter Marris expands on that theory to state that people also connect meaning to their attachments and develop a resistance to change (Katz & Sidell, 1994). Colin Murray Parkes further developed the theory on death and dying by introducing a theory of 'psycho-social transitions' which attempts to understand those changes that greatly affect and change people's lives. Major losses require people to make these transitions and also to rethink the expectations they have of their lives. Also, many writers have described the stages of grieving as: shock and disbelief, pining, and reorganization and reintegration (Katz & Sidell, 1994).

Theories on death and dying introduced the concept of dying with dignity and supported the growth of the hospice movement. The concept established a set of values

and objectives around which collective action could be built. It provided an ideological base for the hospice movement. The philosophy of dying with dignity also provided support and leadership for medical professions and occupations. It also linked the hospice movement to other networks and institutions already in existence which share the same philosophy on death and dying issues (Fulton & Bendiksen, 1994). The theoretical and conceptual framework regarding death and dying issues greatly impacted the development of hospice care in the United States.

### **C. Anticipatory Grief Model**

Therese Rando (1986) provides a definition of anticipatory grief as a concept involving the processes of “mourning, coping, interaction, planning, and psychosocial reorganization that are stimulated and begin in part in response to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present, and future” (p. 24). It can be experienced by both patients and their families, however, for the purpose of this research study, only the family’s anticipatory grief will be discussed. Anticipatory grief can allow family members to do the following before the actual death occurs: absorb and start dealing with the reality of the death gradually over time; resolve any unfinished business with the dying person; begin to change their assumptions about life and identity; and begin to make plans for the future (Rando, 1984). The family may also experience a heightened concern for the terminally ill person, depression, rehearsing the death in their minds, and making efforts to begin to adjust to the consequences of the death.

The concept of anticipatory grief has been controversial and met with mixed opinions, as some people do not believe it actually exists. There are some cautions to

consider, especially that not all people facing the death of a loved one will experience anticipatory grief. Also, it is not necessarily a positive experience. It can be either helpful or harmful for grievors and it may uncover some ambivalent or negative feelings that may lead to more pronounced or difficult feelings after the death (Rando, 1984). Despite some controversy, the literature does suggest that some people do grieve the loss of a loved one prior to the actual death (Huber & Gibson, 1990). This, in turn, may possibly lead to a more bereft grief process following the death.

Understanding the concept of the anticipatory grief model enables professionals assisting in the care of terminally ill patients to assist families through this difficult time. These professionals are frequently hospice care staff members and research reveals that hospice can assist families with anticipatory grief work, which can lead to an easier bereavement process following the death (Huber & Gibson, 1990).

#### **D. Attachment, Loss and Grief Therapy**

Theories on attachment and loss center around Bowlby's concept of attachment as previously described. Bowlby's theory enables professionals to conceptualize how people make strong affectional ties with others and to understand the strong emotional reaction when those ties are threatened or broken (Worden, 1991; Sable, 1992). Bowlby suggests four main phases of mourning in his effort to explain the grief process following a loss. These phases include: numbing, yearning and searching, disorganization and despair, and reorganization (McNeil, 1995; Sable, 1992). Schoenberg (1980) describes the impact of a loss as causing the mourners to feel immobilized, unable to let go of the past, and unable to make new commitments. Stroebe and Stroebe (1987) state that when loved ones die, the survivors need to invest all their energy to sever the ties to the loved

ones and let go. This often results in the mourners having to withdraw from the real world as they deplete all of their excess energy during this process.

Sometimes survivors will seek assistance with their grief work and the goal of therapy in this situation is to provide the mourners with an opportunity to face loneliness, anxiety and emptiness in a safe environment where they feel understood and supported (Leick & Davidsen-Neilsen, 1991). Grief can be a long process for survivors and it varies with each individual. Grief can become clinically relevant when chronic mourning occurs and the process is exceptionally prolonged and extremely intense (Stroebe & Stroebe, 1987). Chronic mourning is characterized by poor physical health, difficulty in revising life's plans and goals, difficulty maintaining good relationships, and intensified symptoms of anger, depression and anxiety (Sable, 1992). The goal of therapy in this situation is to identify and understand what is impeding the adjustment so that the mourning process can be completed. The survivors need to explore experiences related to the lost loved one. The therapist's role is again to encourage and support the survivors, provide a safe setting, and be attentive and sympathetic (Sable, 1992).

## **IV. Methodology**

### **A. Introduction**

This research study seeks to answer the following research questions:

What are the needs of family members of terminally ill patients?

What benefits does hospice care provide the family members of terminally ill patients?

Is hospice care effective in assisting to ease the bereavement process for families of terminally ill patients?

It is an exploratory study done to attempt to provide support for the use of hospice care and to increase the awareness of the hospice philosophy and services it offers. The needs of family members were identified through the literature review. These needs were formed into statements and participants completing the self-administered questionnaire were asked to rate how beneficial they feel hospice was in assisting to meet those needs. Some questions on the self-administered questionnaire focus on the grief and bereavement of the families to discover if they feel hospice has assisted them through some of their grieving process.

### **B. Operational Definitions**

The following are the operational definitions of the key terms in this research study.

Hospice care: A philosophy of comfort care provided to patients with a life expectancy of six months or less and their family members. It is provided when there is no further available treatment for the patients or they choose to forego any further treatment for their illness. It can be provided in the patient's or family's home, the

hospital, a long-term care or residential facility, or a community home specifically for people with a terminal illness. It emphasizes the health and care of the family as well as the patient and provides supportive services focused on meeting the needs of both populations. It offers supplemental care to assist the family or the staff already in place. Hospice continues to follow and offer services to the family after the death occurs to assist with the grief and bereavement process. This philosophy of care is consistent with that of the hospice program through which this study is being conducted, and is also consistent with the philosophy stated by the National Hospice Organization.

Family: As previously defined in this paper, family will include anyone the patients choose to have involved in their care. This includes any relatives or individuals who have significant ties to the patient and assist or are interested in the care of the patients.

Terminal illness: Defined as a disease which limits the life expectancy of someone to six months or less. A terminal illness can be, but is not limited to, one of the following: cancer, end-stage dementia, Alzheimer's disease, end-stage lung disease (ESLD), Congested Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), and acquired immune deficiency syndrome (AIDS).

Patients: To be defined specifically for the purposes of this research study as those individuals with a terminal illness who were enrolled in the hospice program involved in this study and died between February 1, 1996 and July 31, 1996.

Benefits: The needs of the family members of terminally ill patients were identified through the literature review for this research study. They will be presented, by way of a questionnaire, to the primary care persons of those patients inclusive in the

description above. Benefits will be defined as the needs the primary care persons identify on the questionnaire as being met with the assistance of the hospice team.

Primary care persons (PCPs): Those individuals most involved in the patients' care. They either provided the care in their homes or were the people most knowledgeable about the care if received in another location. These people are identified on the medical record of the patients for the area hospice program involved in this study.

The area hospice program: A program of care servicing patients with a terminal illness and their families. It is located in the Twin Cities area of Minnesota, provides care in a variety of locations as previously defined, and serves a 30-mile radius. It provides care to people of all ages and a variety of diagnoses. The program's services are covered under the Hospice Medicare Benefit, other insurance coverage, or grant money. This program follows the philosophy of hospice care described above under the definition of hospice care, which is consistent with the philosophy designated by the National Hospice Organization. It offers a team of nurses, social workers, home health aides, volunteers, homemakers, chaplains, and a medical director. It can also offer the services of a physical, occupational, speech or music therapist, dietitian, massage therapist, or grief counselor. This interdisciplinary team is directed and supervised by a primary physician and primary hospice nurse, which provides consistency and continuity of care. This hospice program approaches care by supporting the patient and family and attempting to make them live as comfortably as possible. It assists the patient and family to prepare for the impending death, and assists the family after the death by offering bereavement follow-up services.

### **C. Research Design**

This research project is an exploratory study. It attempts to explore the benefits of hospice care for family members of terminally ill patients. The research design is limited in scope as information is obtained from participants involved in one particular hospice program rather than a variety of similar programs around the area. This exploratory study does not use a control group, as all participants will have received the hospice benefit. This study explores the use of hospice care by discovering whether the services it provides are helpful and, specifically, what components of the care are viewed as helpful by participants.

This research study uses a self-administered questionnaire as the data collection tool. This questionnaire consists mostly of quantitative methods, with some qualitative approaches included. The quantitative methods use a Likert-type scale format to discover what primary care persons of terminally ill patients find most and least helpful about the hospice care they received. The qualitative methods consist of some open-ended questions used to allow participants to expand on their experiences and provide any suggestions or recommendations on how to improve the service of hospice care by this hospital.

The units of analysis in this research study are individuals and, more specifically, the primary care persons of patients who were enrolled in the hospice program and died between February 1, 1996 and July 31, 1996. This project is a cross-sectional study with an exploratory purpose. It involved mailing a self-administered questionnaire to participants, which was a one-time commitment on their part. It included a specific group of predetermined individuals whose family members died within a specified period



of time. The intention of the self-administered questionnaire was to determine what benefits those individuals found hospice care provided them.

#### **D. The Study Population**

The study population was selected from the families of patients who received hospice care through this area hospice program. The majority of the participants will have cared for their loved one at home. However, the death does not necessarily need to have occurred in the home. Sometimes, when the care becomes too much for the family to manage at home, the patient will be admitted to a residential facility, cancer home, nursing home or the hospital, but the original hospice team continues to follow. Also, the care does not need to have originated in the home. Hospice will follow patients at the onset in a variety of locations. The study is limited to the time-frame of the death occurring during a six month period, between February 1, 1996 and July 31, 1996. This allowed time for people to know where they are at in the bereavement process and be able to reflect on the care received, but not too long that their memory has faded. The family members asked to participate in the study were those people who were most responsible for the patients during the time of hospice involvement. These individuals are listed in the patients' medical records as the primary care persons (PCPs).

#### **E. The Sample**

The sample was obtained with the assistance of a staff person and a volunteer at the hospice program involved in this study. The staff person generated a list of all primary care persons (PCPs) for patients who were enrolled in the home hospice program and died between February 1, 1996 and July 31, 1996. The self-administered questionnaire was mailed to all PCPs in this time-frame, and the sample size was 128.

The sampling frame for the list of participants was a census file of all deaths of patients who had been enrolled in this hospice program.

The method for obtaining this sample employed purposive sampling, which is a non-probability sampling technique. This method was utilized due to the principal investigator's own knowledge of the topic obtained from research done on the needs of family members of terminally ill patients and how hospice care may benefit them. Given this knowledge, the sampling frame was chosen as the best possible population to respond to the questionnaire on this topic. The time-frame of the death having occurred between six months and one year ago was selected to allow the participants time to have made some progress in their bereavement process and better know how to rate the hospice care received. This time-frame was chosen also to be sensitive to their bereavement process and have them respond some time after the death when they may be emotionally more stable and able to reflect on the care received.

#### **F. Data Collection**

The data collection tool used in this research study was a self-administered questionnaire. The questionnaire was designed to obtain the perceptions of the primary care persons on the hospice care they received for their loved one. It attempted to discover what benefits they feel hospice care provided to them and elicit any suggestions they may have that would improve the care received. The questionnaire was mailed by a volunteer at the hospital to all primary care persons (PCPs) of patients who were enrolled in the home hospice program and died between February 1, 1996 and July 31, 1996. An initial cover letter (see appendix B), instructions for completing the questionnaire (refer to appendix D), the self-administered questionnaire (see appendix E), and a self-

addressed, stamped return envelope, were all mailed to the PCPs on February 21, 1997 to their homes.

A follow-up letter (refer to appendix C) was mailed along with an identical instruction page and questionnaire, and another self-addressed, stamped return envelope, two weeks later on March 10, 1997 to those PCPs who had not returned the first questionnaire mailed to them. This was determined through a coding system. All outside and return envelopes were coded with a number and the volunteer mailing out the questionnaires tracked each number with the PCP to whom that envelope was mailed. The same number that was on the outside envelope was on the return envelope inside. When the principal investigator received the returned questionnaires, all numbers that were returned were given to the volunteer. The volunteer then crossed each of those PCPs off of the second mailing list.

The self-administered questionnaire was a one-time commitment on behalf of the primary care persons and once they returned it, their role in this research study was complete. It was estimated to take the PCPs approximately twenty (20) minutes to complete. The completed questionnaires were then returned in the stamped envelope provided to a campus mail box at Augsburg College. The deadline to return the second mailing of the questionnaire was March 24, 1997. All completed and returned questionnaires were kept in a locked drawer in the principal investigator's home until completion of the study. They will be shredded no later than August 30, 1997.

### **G. Instrument Design**

The instrument used in this research study was the self-administered questionnaire mentioned above. The questionnaire consisted of mostly quantitative

methods in the form of a Likert-type scale. The literature review conducted for this research study identified some key needs of family members of terminally ill patients. These needs were presented in the questionnaire in the form of statements, which participants were asked to respond to how beneficial hospice care was in assisting to meet those identified needs. The questionnaire was also developed with regard to the theoretical framework on death and dying issues, which support that care be provided to help patients die with dignity. Theories on anticipatory grief and the bereavement process of families were also considered in the questionnaire as some questions focused specifically on their bereavement process.

Participants were asked to rate their agreement with each statement on the following scale: strongly disagree, disagree, undecided or unsure, agree or strongly agree. The questions were presented in both positive and negative forms, to prevent participants from getting in a habit of answering in a particular way. Qualitative methods, in the form of open-ended questions, were interspersed in the questionnaire to allow participants to elaborate on the hospice care received. Background, demographic information was obtained at the conclusion of the study. The questionnaire consisted of questions pertaining to the medical, physical and emotional needs of the patients and family members.

The questionnaire began with statements related to their physical needs, and attempted to begin with the most interesting and easy to answer questions. This was done with the intention of drawing the interest of the primary care persons to respond to the questions. Care was taken to ask non-threatening questions, with sensitivity to the tragic event for which hospice care was needed. The questionnaire was spread out and

uncluttered to make it easier for the participants to read. The Likert-type scale used provided a matrix question format, with most questions requiring a similar response on the scale provided. This was done to make it quicker and easier for the participants. A clear, concise instruction page to completing the questionnaire was included with each questionnaire, providing simple instructions and suggestions for completing it. Please refer to appendix D for a copy of the instruction page and appendix E for a copy of the questionnaire mailed to the primary care persons of patients who received hospice care.

#### **H. Contact of Subjects and Pre-Test**

A volunteer through the hospice program made contact with the sample of all primary care persons (PCPs) of patients who were enrolled in their program and died between six months and one year ago. Contact was made through the mailing of the initial and follow-up cover letters, instructions, return envelopes, and questionnaires to their homes. This was done to ensure anonymity as the principal investigator did not have any knowledge of who was receiving the questionnaires. Participants were asked in the initial and follow-up cover letters, and in the instructions to the questionnaire, to not provide any identifying information on the questionnaire or the return envelope to ensure their anonymity. The principal investigator did not work directly with any of the respondents or their loved ones as the time-frame for those receiving the questionnaire was before the principal investigator began interning at this hospice program. Please refer to appendices B and C for copies of the initial and follow-up cover letters mailed to all participants.

The questionnaire was pre-tested by four people who were familiar with hospice care and had experienced it in their own family, or with people they cared for and

considered part of their family. These individuals were acquaintances of the principal investigator. Some suggestions and feedback were provided and minimal changes were made to the questionnaire after the completion of the pre-testing.

### **I. Protection of Human Subjects**

This research study was approved by and is being done in cooperation with the hospice program involved in this study. Please refer to appendix A for a copy of the letter of support from the hospice program signed by the Director of Patient Services and the principal investigator's supervisor for her internship at the program. A research proposal, requesting the approval for the use of human subjects in research was also submitted to and approved by the Institutional Review Boards (IRBs) at Augsburg College and the hospital, and also the Protocol Review Committee (PRC) at the hospital.

There is a bereavement team through the hospital that follows the families of patients who have received hospice care through their program. Mailings, bereavement calls, grief classes, an ongoing grief support group, and individual or family counseling are offered by this team. This team will follow families for up to one year following the death and longer if deemed necessary or requested. The phone number of how to contact members of this team was provided in the initial and follow-up cover letters mailed to the sample group. It was emphasized and encouraged in these letters that if the questionnaire triggers some difficult feelings or emotional distress in them, they should call that number to contact one of the members of the bereavement team, or attend the support group for support and assistance. The time, day and location of the ongoing support group was also provided in the letters.

Participants were asked in the instructions page to return the questionnaire unanswered in the envelope provided if they did not stay with or in close proximity to their hospice patient and participate in his/her care. Participants were also informed through the initial and follow-up cover letters that their responses would be strictly confidential and only read by the principal investigator who did not know their identity, and who would shred the contents of the questionnaires when the study is completed, and no later than August 30, 1997. It was also explained that their responses on the questionnaire would be shared with the staff at the hospice program in summarized form only, and neither the principal investigator nor the staff at the hospital would know whether or not they participated in the study. The volunteer doing the mailing would have that knowledge for the purpose of the coding system, but would not have access to the questionnaires upon their return. This was done to reduce the risk of social desirability. Participants were informed that the completion and return of the questionnaires on their behalf would indicate their consent to participate in this research study as well as conclude their role in the study. Please refer to appendices B and C for copies of the initial and follow-up cover letters mailed to participants.

### **J. Analysis**

The data were obtained for this research study from the completed and returned questionnaires by the primary care persons. Analysis was done by first separating the data into the following two sections: quantitative data and qualitative data. The quantitative data came in the form of the responses to the questions using the Likert-type scale. Descriptive statistics were used to summarize the characteristics of the data and determine which needs the participants felt were met with the assistance of the hospice

team. Tables were made to identify and evaluate the responses to each question pertaining to the Likert-type scale. Percentages were calculated to determine the most and least prominent benefits hospice can provide to family members of terminally ill patients according to the participants in this research study.

The qualitative data were in the form of the open-ended questions on the questionnaire. Analysis of these data was done to detect particular themes or patterns in those responses. They were presented in summarized form. Particular attention was paid to any comments or suggestions the participants gave for improving the quality of services provided by the hospice team. All responses were pooled together and reported on by way of summarized form, describing the similar themes found through the analysis.



## **V. Presentation Of The Findings**

### **A. Introduction**

The research questions being addressed and answered through the presentation of the findings are as follows:

What are the needs of family members of terminally ill patients?

What benefits can hospice care provide the family members of terminally ill patients?

Is hospice care effective in assisting to ease the bereavement process for families of terminally ill patients?

The self-administered questionnaires were mailed to the primary care persons, completed by their own choice on a voluntary basis and returned to Augsburg College at the principal investigator's attention. The deadline for returned questionnaires was March 24, 1997. One hundred and twenty-eight questionnaires were mailed to the primary care persons, out of which 88 were returned. Six of the 88 questionnaires were returned completely blank and unanswered, leaving 82 to be used for the collection of data. This indicates a 64% response rate. Participants were instructed to return the questionnaires unanswered if they were not with or in close proximity to the hospice patient and did not participate in the care of their loved one. Several participants left some questions unanswered or stated it did not apply to their situation, but responded to the majority of questions. The number of participants who answered each question is represented in the respective table for the question.

Both quantitative and qualitative data were collected in this research study by way of the self-administered questionnaire and the results are presented in this chapter. The

quantitative data were obtained by a Likert-type scale and have been converted into tables displaying the percent response in each category to each of the questions. The Likert-type scale has been treated as an interval level, assuming there is equal distance between the units of measurement (strongly disagree, disagree, undecided, agree, and strongly agree). The qualitative data were obtained through open-ended questions which provided the participants with an opportunity to give suggestions or comments and list what they found most and least helpful about the care received. These comments are presented in summarized form in this chapter, with particular attention given to themes and patterns.

## **B. Quantitative Data**

### Demographics

Data were obtained from 82 of the 88 returned questionnaires as six were returned completely blank. However, the number of responses to each question is indicated throughout this chapter as some participants left some of the questions blank but answered the majority of them. The percentages are based on the total number of responses to each question. The majority (50 or 64%) of participants were female, with 28 or 36% being male and 10 of the participants leaving that question unanswered (please refer to graph #1 on page 92). The participant's relationship to the hospice patient was one of the demographic questions asked with the following data obtained: 50 (65%) out of the 77 who responded to this question were a spouse to the patient, 14 (18%) participants were a child, 5 (7%) were a parent, 4 (5%) put themselves in the

“other” category, 2 (3%) were a partner, 1 (1%) was a friend and 1 (1%) was a significant other (please refer to graph #2 on page 93).

The number of days the hospice patient was enrolled in the program ranged from one day to 91 days or longer. The following data were obtained regarding the length of enrollment in the program, with 77 participants responding to this question: 35 (45%) stated the patient was enrolled from 7 to 30 days, 24 (31%) were enrolled from 31 to 90 days, nine (12%) were enrolled less than seven days and nine (12%) participated in the program for 91 days or longer. Half of the hospice patients were enrolled in the program between 1 and 30 days, with 37% enrolled 31 days or longer (please refer to graph #3 on page 94).

The majority of participants were 51 years of age or older. No one was under 31 years of age and no one was older than 90 years. The following findings were discovered from 78 responses: 18 (23%) of the participants were either between the ages of 41 and 50 or 71 and 80, 17 (22%) were between the ages of 61 and 70, 13 (17%) were between 51 and 60, nine (12%) were between 31 and 40 and three (4%) were between the ages of 81 and 90 (please refer to graph #4 on page 95).

#### Medical and Physical Needs

The following tables and explanations were obtained from the first section on the questionnaire pertaining to the medical and physical needs of the hospice patients and the primary care persons. Participants were asked to circle a number for each statement corresponding with a scale of strongly disagree (1), disagree (2), undecided (3), agree (4) or strongly agree (5). Adjusted frequencies are used in the tables, as the percentages are based on the number of participants who responded to one of the above options for each

question. Two questions in this section, numbers one and seven, added a category of “not applicable”, as they referred to care received in the home and not all patients were cared for at home. Some participants added their own category of “not applicable” for other questions, but the percentages are based on the number of responses to the categories provided.

**Table A-1**

N = 81

A-1. Hospice assisted in providing me with the knowledge and skills necessary to care for my loved one at home.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	NA	Total
0	1	3	32	37	8	81
0.0%	1.2%	3.7%	39.5%	45.7%	9.9%	100.0%

As shown in Table A-1, 81 of the 82 participants who returned a completed questionnaire responded to this question. A significantly high percentage (85.2%) supported the efforts of hospice care in providing them with the knowledge and skills necessary to care for their loved one at home, as 39.5% agreed and 45.7% strongly agreed with the statement. Eight, or 9.9%, stated that the statement did not apply to their situation, as not all hospice patients are cared for at home. The mean response to this question on the Likert-type scale was 4.4.

**Table A-2**

N = 81

A-2. Before hospice became involved, I had difficulty obtaining necessary information from my health care professionals.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
16	41	11	8	5	81
19.8%	50.6%	13.6%	9.9%	6.2%	100.1%

\*total does not equal 100% due to rounding

Table A-2 shows that out of the 81 participants who responded to this question, 57 (70.4%) did not feel they had difficulty obtaining information from their health care professional before the involvement of hospice care, as 50.6% disagreed and 19.8% strongly disagreed with the statement. Eleven people (13.6%) were undecided on this question. The mean response on the Likert-type scale was 2.3, indicating the majority disagreeing with the statement.

**Table A-3**  
N = 80

A-3. The hospice team aided me in obtaining necessary information regarding the disease and physical needs of my loved one.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
2	5	4	49	20	80
2.5%	6.3%	5.0%	61.3%	25.0%	100.1%

\*total does not equal 100% due to rounding

Table A-3 demonstrates that although the vast majority denied having difficulty obtaining information before hospice involvement, a large majority - 69 out of 80, or 86.3% - did feel the hospice team aided them in obtaining necessary information about the disease and physical needs of their loved ones. The mean response was 4.0 on the Likert-type scale.

**Table A-4**  
N = 81

A-4. The hospice team lacked the ability to diminish the demands placed on me in the care of my loved one.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
30	38	7	2	4	81
37.0%	46.9%	8.6%	2.5%	4.9%	99.9%

\*total does not equal 100% due to rounding

As seen in Table A-4, this statement was worded in a negative form to prevent people from answering in a habitual manner. Sixty-eight (83.9%) did not agree that the hospice

team lacked the ability to diminish the demands placed on them, with 38 (46.9%) disagreeing and 30 (37.0%) strongly disagreeing with the statement. Seven (8.6%) were undecided, and a very small percentage - 7.4% - either agreed or strongly agreed with the statement. The mean, or average response on the Likert scale was 1.9.

**Table A-5**

N = 76

A-5. Hospice offered trained staff to provide me with a break, or time away when I needed it.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
4	7	8	33	24	76
5.3%	9.2%	10.5%	43.4%	31.6%	100.0%

As shown in Table A-5, only 76 of the 82 completed questionnaires returned had responses to this question. Again, 88 questionnaires were returned, however, six were completely blank. One individual responded that this question did not apply to his/her situation, even though "NA" was not provided as a possible response to this question. That was not considered a response. Fifty-seven (75.0%) did agree or strongly agree that hospice provided them with a break or time away when needed. A total of 14.5% disagreed or strongly disagreed with this statement. The mean response was 3.9.

**Table A-6**

N = 74

A-6. The trained staff also enabled me to get some rest, so I was less physically exhausted than I feel I would have been without hospice.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
3	13	15	23	20	74
4.1%	17.6%	20.3%	31.1%	27.0%	100.1%

\*total does not equal 100% due to rounding

Table A-6 indicates that 74 participants responded to this statement. Three others did respond, however, stated that it did not apply to their situation. The responses were more

dispersed than previous ones, with 58.1% either agreeing or strongly agreeing with the statement and 21.7% either disagreeing or strongly disagreeing with it. A larger percentage - 20.3% - were undecided. The average response was 3.6, indicating the slight majority in agreement with the statement.

**Table A-7**

N = 82

A-7. I had difficulty obtaining the medical equipment necessary to care for my loved one at home.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	NA	Total
40	25	0	4	3	10	82
48.8%	30.5%	0.0%	4.9%	3.7%	12.2%	100.1%

\*total does not equal 100% due to rounding

As shown in Table A-7, sixty-five (79.3%) either disagreed or strongly disagreed that they had difficulty obtaining medical equipment. Ten (12.2%) stated that this did not apply, which was a possible response to this question, as they either did not need medical equipment or did not care for their loved one at home. Only a small percentage (8.6%) agreed in some form with this statement. The mean response on the Likert-type scale was 1.7.

**Table A-8**

N = 79

A-8. The hospice staff explained the physical changes I might see in my loved one as he/she approached death, which helped to prepare me for his/her final days.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
3	13	4	36	23	79
3.8%	16.5%	5.1%	45.6%	29.1%	100.1%

\*total does not equal 100% due to rounding

As seen in Table A-8, the majority of participants - 59 or 74.7% - agreed that hospice was helpful in explaining the physical changes the patient might experience as he/she

approached death. On the other hand, 20.3% disagreed in some form with this statement.

The mean response was 3.8, which shows the majority agreeing with the statement.

**Table A-9**

N = 77

A-9. Hospice could have kept me better informed about my loved one's condition during his/her decline.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
18	37	9	12	1	77
23.4%	48.1%	11.7%	15.6%	1.3%	100.1%

\*total does not equal 100% due to rounding

Table A-9 indicates that 77 participants responded to this question. Two other participants did respond but said this question did not apply to their situation. Thirteen, or 16.9%, agreed with the question. The majority, 55 or 71.5%, disagreed or strongly disagreed that hospice could have kept them better informed during their loved one's decline. Nine (11.7%) were undecided. The mean response for this question was 2.2.

**Table A-10**

N = 80

A-10. I feel the hospice team was dishonest with me at times.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
56	17	2	2	3	80
70.0%	21.3%	2.5%	2.5%	3.8%	100.1%

\*total does not equal 100% due to rounding

As seen in Table A-10, a very high majority, 73 (91.3%), did not feel that the hospice team was ever dishonest with them, with 70.0% of those individuals strongly disagreeing with the statement. Only 6.3% agreed or strongly agreed and one person stated it did not apply. The mean response was 1.5, indicating the vast majority disagreeing with this question.



**Table A-11**

N = 80

A-11. I felt comfortable and able to have open communication with the hospice team regarding my loved one's condition.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
0	3	0	37	40	80
0.0%	3.8%	0.0%	46.3%	50.0%	100.1%

\*total does not equal 100% due to rounding

As shown in Table A-11, no one strongly disagreed or was undecided about this question, and only three (3.8%) disagreed. The vast majority, 77 or 96.3%, either agreed or strongly agreed they felt comfortable and able to have open communication with the hospice team. Again, one person stated it did not apply. The average score, 4.4, demonstrates the large number of participants in strong agreement with the statement.

Emotional Needs

**Table B-1**

N = 78

B-1. Hospice was ineffective in assisting me to cope with my loved one's changing mental capacity.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
21	39	6	7	5	78
26.9%	50.0%	7.7%	9.0%	6.4%	100.0%

Table B-1 shows the majority of 76.9% did not feel hospice was ineffective in assisting them to cope with the changing mental capacity of their loved ones. A small percentage of 15.4% did agree with the statement, 7.7% could not decide and one person felt it did not apply to his/her situation. The mean point score on the scale was 2.2, showing the strong number disagreeing with the statement.

**Table B-2**

N = 79

B-2. Hospice aided me in coping with my loved one's changing physical condition.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
1	4	5	46	23	79
1.3%	5.1%	6.3%	58.2%	29.1%	100.0%

With this question similar to the one above but worded in the positive form, Table B-2 shows a very strong majority, 87.3%, agreed that hospice helped them cope with the changing physical condition of their loved one. Only 6.4% disagreed and 6.3% were undecided. The average score, 4.1, demonstrates the majority being in agreement with the statement.

**Table B-3**

N = 78

B-3. The hospice staff could have offered more opportunity to discuss my fears and concerns.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
17	44	7	9	1	78
21.8%	56.4%	9.0%	11.5%	1.3%	100.0%

Table B-3 shows that out of 78 participants responding to this question, 61 or 78.2% did not feel the hospice team could have offered more opportunity to discuss their concerns. 12.8% did feel they were not offered enough time to discuss their concerns, while 9.0% were unsure. Again, one person felt it did not apply. The average score, 2.1, indicates the majority in disagreement with the statement.

**Table B-4**

N = 78

B-4. I feel the hospice team helped me to work through some of the grief before the death occurred.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
3	11	18	35	11	78
3.8%	14.1%	23.1%	44.9%	14.1%	100.0%

As Table B-4 demonstrates, the responses to this statement were quite divided, with 17.9% disagreeing in some form, 59.0% agreeing in some form and a substantial 23.1% undecided. Still, the majority agreed (44.9%) or strongly agreed (14.1%) that hospice assisted them with some of their grief before the death occurred. The average point score was 3.5.

**Table B-5**

N = 79

B-5. I feel my grief immediately following the loss was less than it would have been had we not received hospice care.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
2	11	17	28	21	79
2.5%	13.9%	21.5%	35.4%	26.6%	99.9%

\*total does not equal 100% due to rounding

Again, responses were divided, however, as Table B-5 shows, the majority, 49 or 62.0%, agreed or strongly agreed that they experienced less grief right after the death with the help of hospice involvement. Thirteen, or 16.4% either disagreed or strongly disagreed while 21.5% were unsure. One person said it did not apply as hospice was only involved for one day. The average point score for this statement was 3.7, indicating slightly more agreement with this statement than the one above regarding grief before the death.

**Table B-6**

N= 79

B-6. I feel my grief today is less than it would have been had we not received hospice care.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
2	7	24	28	18	79
2.5%	8.9%	30.4%	35.4%	22.8%	100.0%

Table B-6 indicates that the majority of participants, 46 or 58.2%, either agreed or strongly agreed that they are experiencing less grief at this time (six to twelve months after the death) than they feel they would be experiencing if they had not received hospice. A high 30.4% could not be sure and 11.4% did not agree. The average score of 3.7 indicates the majority in agreement with the statement.

**Table B-7**

N = 75

B-7. I wanted my loved one to remain at home until his/her death.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
3	6	3	26	37	75
4.0%	8.0%	4.0%	34.7%	49.3%	100.0%

As seen in Table B-7, a very high majority of participants, 63 or 84.0%, agreed that they wanted their loved one to remain at home, while 9 or 12.0% did not want this and 4.0% were not sure. The mean score of 4.2 indicates the strong agreement with this statement. Only 75 of the participants responded to this question.

**Table B-8**

N = 76

B-8. Hospice worked hard to attempt to make the above ( #7 ) possible.

Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
2	0	6	26	42	76
2.6%	0.0%	7.9%	34.2%	55.3%	100.0%

Table B-8 shows a high majority of 89.5% agreed or strongly agreed that hospice worked hard to help keep their loved one at home, with 7.9% unsure and only 2.6% disagreeing. The mean score on the Likert-type scale was 4.4, demonstrating the large number in agreement with the statement.

Grief/Bereavement Options

Question number B-9 was left blank by the majority of participants. They were provided with a list of grief/bereavement options offered by the hospital. The options included letters/mailings, bereavement calls, grief classes, support group, and counseling. Participants were asked to respond on the Likert-type scale of strongly disagree, disagree, undecided, agree or strongly agree, only to those options in which they had participated. They were asked to respond to the statement, “I feel this grief/bereavement option was beneficial for me”. The following data were obtained:

**Table B-9a**  
N = 40

Letters/Mailings:

Strongly Disagreed	Disagreed	Undecided	Agreed	Strongly Agreed	Total
1	1	8	12	18	40
2.5%	2.5%	20.0%	30.0%	45.0%	100.0%

Table B-9a shows that only 40 participants responded to this option, with 30.0% (n = 12) agreeing and 45.0% (n = 18) strongly agreeing that receiving letters and mailings from the program following the death was beneficial for them. A substantial 20.0% were unsure if it was beneficial and 5% did not feel it was helpful for them. The average score on the Likert-type scale was 4.1, indicating the majority of those who responded were in agreement with the statement.

**Table B-9b**

N = 41

Bereavement Calls:

Strongly Disagreed	Disagreed	Undecided	Agreed	Strongly Agreed	Total
0	2	5	10	24	41
0.0%	4.9%	12.2%	24.4%	58.5%	100.0%

Forty-one participants responded to this option, and Table B-9b shows that the majority of 82.9% agreed or strongly agreed that the bereavement calls they received following the death were beneficial for them. Five (12.2%) were unsure and only 2 or 4.9% disagreed with the statement. The mean score was 4.4 on the Likert-type scale.

**Table B-9c**

N = 20

Grief Classes:

Strongly Disagreed	Disagreed	Undecided	Agreed	Strongly Agreed	Total
1	1	3	6	9	20
5.0%	5.0%	15.0%	30.0%	45.0%	100.0%

Table B-9c indicates that a small number of 20 participants responded to this option, and out of those 20, 15 or 75% agreed or strongly agreed that they felt the grief classes were beneficial for them. Two individuals (10%) did not agree and 3 (15%) could not be sure. The average response on the point scale was 4.1.

**Table B-9d**

N = 18

Support Group:

Strongly Disagreed	Disagreed	Undecided	Agreed	Strongly Agreed	Total
1	1	3	6	7	18
5.6%	5.6%	16.7%	33.3%	38.9%	100.1%

\*total does not equal 100% due to rounding

Only 18 participants responded to the support group option, and Table B-9d shows that out of 18, 13 or 72.2% felt the group was beneficial for them. Two people, or 11.2% disagreed with the statement and 3 or 16.7% were unsure. The mean score was 3.9.

**Table B-9e**  
N = 20

Counseling:

Strongly Disagreed	Disagreed	Undecided	Agreed	Strongly Agreed	Total
1	1	4	7	7	20
5.0%	5.0%	20.0%	35.0%	35.0%	100.0%

Table B-9e shows that 20 participants responded and 70% (n = 14) agreed or strongly agreed that the counseling they received through the program was beneficial. Two people (10%) did not feel it was beneficial, and 4 (20%) were unsure. The average score on the Likert-type scale was 3.9, indicating the majority in agreement.

The data show a low response rate for all grief/bereavement options, which could demonstrate a low participation level in the grief/bereavement options since participants were asked to respond only to those in which they had participated. However, looking at the percentage that did respond, a high majority of participants felt the options they participated in were beneficial. The agree and strongly agree categories had a much larger percentage than the disagree and strongly disagree categories for all options.

The final quantitative statement on the questionnaire asked those participants to whom it was applicable to respond to the statement, “hospice was sensitive to varying cultural, spiritual, ethnic and language needs”. Again, there was a low response rate for this question, with 39 participants responding. For those who did respond, no one disagreed or strongly disagreed, 17.9% (n = 7) were undecided, 48.7% (n = 19) agreed,

and 33.3% (n = 13) strongly agreed. A positive response was received by those who responded.

### **C. Qualitative Data**

There were five open-ended questions asked on the self-administered questionnaire. These five questions elicited the qualitative data. Participants were provided with an opportunity to add comments or suggestions after section A, medical and physical needs, and after section B, emotional needs. They were also asked to list what they found most and least helpful about the hospice involvement, and to list any recommendations they may have for improvement to the hospice program. Again, 88 out of the 128 mailed questionnaires were returned, and six were returned completely blank, leaving 82 (64%) for collection of data. Overall, a high response rate was received on the qualitative, open-ended questions. These responses are summarized below.

The first open-ended question appeared on the questionnaire at the end of section A as follows:

**1) Please add any comments/suggestions you may have regarding the assistance of the [name of hospital] hospice team in meeting the medical and physical needs of you and your loved one.**

A 50% response rate was received, as 41 out of the 82 completed questionnaires had responses to this question. Given the large number of responses and also to protect anonymity, responses are summarized for the purposes of this paper.

#### Positive Comments:

Participants had many positive responses to this question. Several wrote that they felt the hospice team was wonderful, kind, considerate, caring, helpful, dependable,



knowledgeable and loving. One person felt all staff members should be candidates for sainthood. Several people commented that having them available and there if needed by the 24-hour on call system was very helpful and reassuring, and their quick response time was appreciated. One person felt the team was very direct, which was needed and appreciated, while another felt they provided very good support. Several individuals appreciated the assistance which allowed them to care for their loved one at home and helped them to accept the death. Others felt that hospice made a very bad situation manageable, they could not say enough good things about them, and they could not have done it without the assistance of hospice.

Negative Comments/Constructive Criticism:

Comments in this area were fairly unique. Two participants felt the hospice staff could have provided more explanation about the physical changes they would see and the steps during the final days of the patient's life. One person expressed that it was difficult to get necessary equipment delivered timely, and another person felt it was difficult to get medications delivered when needed. Some commented on medication usage, as one wanted better explanation of the effects of morphine and another was uncomfortable using her/his own judgment about dosage of medication which she/he was asked to do. One person commented that he/she could have received better advice from the health care professional on what he/she was really getting into, before agreeing to care for the patient at home. One person wanted the volunteer program expanded, while another felt the home health aides from the contracted home care agency were often ineffective and terrible. One person said the doctor was slow to recommend hospice. A comment was

made that assistance for a two-hour time period was not enough to provide the family with a break.

Other Comments:

Several people commented that they were only involved in hospice a short time (a few days) so they were unable to take advantage of some of the services, while one person did not take advantage of offered services per own choice. One participant commented that the hospice care was provided in a nursing home and she/he had little contact with the hospice team, but would have appreciated more phone calls with updates. One suggested a pamphlet be given out on the dying process. One person commented in retrospect that she wishes she would have gotten rid of some things that were a convenience for her but a discomfort for her husband.

The second question appeared at the end of section B, which was the section on meeting the emotional needs of the patient and family:

**2) Please add any comments/suggestions regarding the use of hospice care in meeting the emotional needs of you and your loved one during this most difficult time:**

A 63% response rate to this question was received as 52 out of the 82 participants responded.

Positive Comments:

Many participants commented that they found the hospice team members helpful, professional, caring, cheerful, prompt, pleasant, truly understanding, supportive, wonderful, considerate and accommodating. Several commented on the nurses

specifically, stating they were good at communicating, interacting with all family members, providing a nonjudgmental environment, and being direct, open and honest but never losing the human element. Two people found the hospice team helpful in making decisions, providing good financial and medical information, and giving reassurance that they were doing the very best they could in caring for their loved one. In general, people felt hospice provided good and much needed emotional support and provided a much needed “lift”.

Some comments were obtained on the grief/bereavement options. One person stated the availability of hospice after the death was equally as important and another mentioned that the follow-up calls were very helpful as it helps to talk to someone about one’s feelings. Someone commented that the grief counselor was sincere, while another discussed how helpful it was to have the chaplain there at the time of death to pray with them at home. The support group was mentioned as being “very helpful” and the family weekend was wonderful for the primary care person and the children. Also, many participants commented that they chose not to participate in the grief/bereavement options that were offered, as they had adequate emotional support.

Negative Comments/Constructive Criticism:

One participant was extremely negative throughout the questionnaire and the response to this question was that hospice is totally ineffective and just a means of getting the dying out of the hospitals to give insurance a relief and so other patients in the hospitals do not have to witness death. Some comments were made that more support, guidance, and suggestions are needed from the very beginning throughout the progression of the disease, while others commented that it would have helped to have been better

prepared that time was so short, and also about the mental changes that may take place. Someone felt that being approached by the chaplain several months later (for a follow-up bereavement call) did not seem appropriate. Another suggestion of providing a written booklet was made. The difficulty in getting a consistent nurse was mentioned, and someone wanted the nurse to come twice a week rather than just one time. Another person felt it would have been helpful to have someone there at the time of death, and to provide more discussion about the dying process and what he/she needed to be doing for the patient during that time.

The last three questions were asked at the end of section B also:

**3) Please list what you found most helpful about the hospice care you received during your loved one's final days:**

A very high 83% of the participants, 68 out of the 82, provided comments to this question. Common responses were that people found the availability of a nurse 24-hours per day through the on-call system, knowing they were there, answering their questions day or night, providing very helpful information, and being attentive, responsive and supportive were the most helpful aspects of the hospice care. Several people felt they were better prepared to care for their loved one at home with the assistance of hospice and their helpful explanations and suggestions. Some appreciated how much was done to keep the patient comfortable, while others mentioned the delivery of medications and equipment to the home was most helpful. Two individuals felt the assistance at the time of death or immediately following it was most helpful.

Several participants commented that the hospice team's gentle guidance through each phase, assessing where they were at in the journey and providing assistance as

needed were extremely helpful. Many people felt the nursing visits were most helpful, while others mentioned the home health aides and volunteers as providing necessary assistance. Pain and symptom management along with taking care of the complicated skilled needs of the patient were also appreciated. Being able to sleep a few hours while help was there and providing assistance with household chores was a relief to some. Compliance with the patient's desire to die at home and doing everything possible to make that happen was most helpful to some, while others appreciated the assistance of getting the patient admitted to the hospital when it became too much to handle. Many comments were made, but having someone available to provide whatever assistance was needed at the time it was needed seemed to be the underlying theme to what was most helpful for these primary care persons.

**4) Please list what you found least helpful about the hospice care:**

A lower response rate, 44% or 36 out of 82, was received for this question, and many people who did comment wrote that they could think of nothing that was least helpful. One individual wrote the emotional support for caregivers and genuine caring by the nurse was least helpful. Some people mentioned the home care agency home health aides were undependable or ineffective, and trained staff members were not available to provide a break. The housekeeping benefit was least helpful for someone, while spiritual discussions was least helpful for another person because the family was not particularly religious. Two participants mentioned that it was difficult to adjust to replacement nurses when their nurse was not available.

Two people also felt they lacked contact with the hospice staff as the care was being provided in a nursing home, but stated they could have benefited from more

assistance. Some felt more preparation about the dying process and what to expect was needed, and someone would have appreciated more suggestions and assistance at mealtime and what types of food to prepare. One person was uncomfortable having the nurse in the room at the time of death and had to ask her to leave, while someone else felt completely alone at that time and did not have a nurse there but would have wanted someone there. One participant was unsure of the role of the social service department, and another felt the hospital hospice staff were too business-like and just when they needed the warmth of the home hospice staff they got to know, it was gone.

The final question asked for recommendations:

**5) If you were to suggest any changes to the [name of hospital] Hospice Program, what would they be?:**

A little over half - 54% or 44 out of 82 - responded to this final open-ended question. Many participants took this opportunity to thank the staff and state they could think of no improvements. Other participants provided some helpful suggestions. Several wanted them to improve the quality of the staff provided by the contracted home health care agency. A few suggestions were made about providing more explanation about the dying process and what to expect at the time of death, with two suggesting the use of written material and two other people wanting more assistance and monitoring of the staff at that time. Two people mentioned that a personal note from the nurse or another staff person following the death would have been welcomed.

Some suggestions about bereavement follow-up included: offer a grief support group during the day, have better people available for counseling, offer male counselors, be available at the time of death, and send the mailings on grief earlier, not two months

after the death. Other suggestions for improvement included: have more people of color on staff, have equipment available and delivered 12 hours/day and 7 days/week, explain the effects of morphine, keep things up front with no surprises, train the nursing home staff in tube feeding procedures and be available to them when that special care is needed, and call family more often with updates when providing care in a nursing home. Some positive suggestions were to continue as is, enlarge the program, find more nurses just like the one we had, and continue to help other people die with dignity.

## **VI. Discussion**

### **A. Introduction**

The purpose of this research study was to explore what benefits hospice care can provide the family members of terminally ill patients. More specifically, this study examined to what extent recipients of hospice care from the home hospice program involved in this study found the services beneficial. It also explored what the primary care persons of patients who were enrolled in this program found most and least helpful and provided an opportunity for them to recommend changes or improvements to the program. This research study also briefly explored whether or not participants felt the assistance of hospice care helped ease some of the bereavement process for them, either before, immediately following or many months after the death of their loved one. An analysis of the data collected reveals that participants for the most part viewed the services of hospice care as beneficial and helpful for them.

### **B. Comparison of Findings to the Literature**

#### The Effects of a Terminal Illness on Families and The Needs of Family Members of Terminally Ill Patients:

The review of literature done for this research study identified many of the effects a terminal illness has on the family members taking care of the patient, and also identified their key needs in that care. Schachter (1992) identified that families lack the knowledge and skills necessary to care for their loved one at home, experience great physical exhaustion and demands of care that they did not fully anticipate or realize before agreeing to care for their loved one at home, and experience psychological distress in dealing with the changing physical and mental condition of the patient.



The results of this study demonstrate the effectiveness of hospice care in assisting families with these difficulties. A majority of the participants in this study responded favorably that the hospice program provided them with the knowledge and skills necessary to care for their loved one at home (85.2%), assisted in diminishing the demands placed on them in that care (83.9%), and also aided them in coping with the changing mental and physical conditions of their loved one (76.9% and 87.3%, respectively). The majority of participants (75.0%) also felt that hospice offered trained staff to provide them with a break, however, just over half agreed that they were able to get some rest and were less physically exhausted with the assistance of hospice. This response may provide a reminder that even though hospice can provide assistance in the home, the majority of the responsibility of care still rests on the family and it is a very burdensome experience.

Some of the research (Kristjanson, 1989; McWhinney, 1989) indicates that families had difficulty obtaining consistent and reliable information from their health care professionals. This study did not support that research as 70.4% of the participants did not feel they had difficulty obtaining necessary information before hospice became involved. However, the majority of 86.3% did feel hospice was beneficial in assisting them in getting necessary information about the disease and physical needs of their loved one. This demonstrates the benefit of hospice care in easing some of the responsibilities of family members of terminally ill patients, as they felt they were able to get necessary information before hospice became involved, but the involvement of the hospice team eased that responsibility for them.

Some documented needs of family members include an opportunity to discuss their personal feelings, concerns and fears (Etten & Kosberg, 1989; Kristjanson, 1989), emotional support, and assistance in getting medical equipment (Kristjanson, 1989). The majority of participants in this research study found hospice was beneficial in assisting to meet these needs. The qualitative data yielded many positive comments regarding the effect of the hospice staff in providing much needed emotional support, being there for them when needed, and listening to their fears and concerns. The quantitative data supported this notion as 78.2% of the participants felt that the hospice team offered ample opportunity to discuss their fears and concerns, with 12.8% stating they could have offered more time and 9% being unsure. A strong 96.3% felt comfortable and able to have open communication with the hospice team. Also, 79.3% felt they were able to get necessary medical equipment with the assistance of hospice care, however, 8.6% did not feel hospice assisted them with this and 12.2% stated it did not apply as they did not require any medical equipment.

Further research supports that if communication is problematic, a lack of trust in the health care professionals can develop (Gordon, 1995; Noggle, 1995). Also, being open and honest and involving the families in the care of the patients can enable families to come to terms with the impending death (Huber & Gibson, 1990). The results of this study support this research. A very high majority of participants, 91.3%, did not feel the hospice team was ever dishonest with them. Also, 71.5% stated that hospice kept them adequately informed about their loved one's changing condition, however, 16.9% did not feel adequately informed about the changing condition. A high majority of 74.7% agreed that the hospice staff did a good job of explaining the physical changes that may occur in

their loved one as he/she approached death, which did help prepare them for the impending death. However, a substantial 20.3% did not feel hospice adequately explained the physical changes. The results of this research study suggest strong support that the use of hospice care can be beneficial in assisting to ease the effects of a terminal illness on family members and also in helping to meet some of their needs.

#### Support for and the Significance of Hospice Care:

Some research presented in the literature review lends support for the use of hospice care for terminally ill patients and their families and demonstrates the significance in doing so. Gardner (1985) suggests that the availability of hospice staff to observe, support, educate and monitor families during this most difficult time can possibly assist them through their bereavement process. Kramer (1992) found that widows whose spouse received hospice involvement experienced less grief both before and after the death than those who did not receive the benefit of hospice care. Research mentioned by Luchins and Hanrahan (1993) suggests that family caregivers receiving hospice care experience less anxiety than those receiving conventional care, and Dawson (1991) and Seale (1991) both did research that demonstrates the significance of hospice care as they found that families voiced greater satisfaction with care provided to their terminally ill member by a hospice program than any other form of care.

Although this study did not compare individuals who received hospice with those who did not, it did obtain some valuable information on the perceptions of those who did receive hospice care. The majority, 59.0%, of the participants in this study agreed that the hospice team helped them work through some of the grief before the death occurred, but a substantial 23.1% were unsure and 17.9% disagreed with the statement. A slightly

larger majority of 62.0% felt their grief immediately following the loss was less than it would have been had they not received hospice care, with still 21.5% unsure and 16.4% disagreeing. A smaller majority of 58.2% felt they are experiencing less grief today (six to twelve months after the death) than they would have been without the assistance of hospice care. However, 30.4% were unable to decide.

These findings lend support for the significance of hospice care as the majority of participants did feel the assistance of hospice care helped them through their bereavement process. However, there was a substantial number of participants still unsure whether or not their grief has been less with the assistance and guidance from the hospice team. More research needs to be done to further address the issue of the assistance of the hospice team through the bereavement process.

Although hospice care is provided in a variety of settings, the most common setting is the patient's home. Part of the philosophy of hospice care is to work hard to keep those patients who desire to remain in their homes there as long as possible (Kastenbaum, 1995; Kirschling, 1989). The results from this study strongly support that this hospice program worked hard to keep patients in their homes. The study first established that 84.0% of the participants wanted their loved one to remain at home until his/her death. Participants then responded to whether or not they felt hospice worked hard to keep the patient at home if that was desired, and 89.5% agreed that they did just that. These results can be interpreted to mean that hospice is successful in carrying out part of its philosophy of care.

### Theoretical Framework:

The anticipatory grief model proposes that family members of terminally ill people can work to start dealing with the reality of the death, resolve any unfinished business with the dying person, begin to change their assumptions about life, and begin to make plans for the future, before the actual death occurs (Rando, 1984). Research reveals that hospice care can assist families with anticipatory grief work, which can lead to an easier bereavement process following the death (Huber & Gibson, 1990). The research findings discussed in the previous section on the grief and bereavement status of participants indicates that the hospice program involved in this study may indeed assist families with this process, as the majority of participants felt they had worked through some of their grief before the death occurred, and felt their grief is less now due to the help of hospice.

The grief work theory and theories on death and dying describe some stages of grief terminally ill patients and their families may experience. These theories introduced the concept of dying with dignity and supported the use of hospice care throughout the United States. The qualitative data yielded some comments on the assistance of the hospice team in helping the patients die with dignity, and their wishes respected. Some of the participants appreciated the assistance of the hospice team so the patient could die at home, and felt they could not have done it without hospice involvement. Some appreciated their honesty and said their directness was needed and appreciated. Reviewing the comments made by participants and what they thought was most helpful about the hospice care they received promotes the idea that this hospice program assists

patients and families through their grief processes and works hard to help the patients die with dignity.

The research presented on attachment, loss and grief therapy describes the phases of mourning as numbing, yearning and searching, disorganization and despair, and reorganization (McNeil, 1995; Sable, 1992). When people in mourning reach out for assistance with their grief work, they need to be provided with a safe environment where they feel understood and supported so they can face their loneliness and anxiety (Lieck & Davidsen-Neilsen, 1991). The bereavement team through this hospital offers grief classes to help families understand what they are experiencing, and a support group and counseling as a safe environment where they can discuss their fears.

The low response rate of participants in this study to questions about these grief/bereavement options may indicate that families are not taking advantage of these services. The letters and mailings on grief go out to all families, although more information is sent to those individuals who were assessed as “high risk” in grief by the hospice team. People who have significant support already established and seem to be dealing well with the death are assessed as “low risk”. Those who answered this question responded favorably that the mailings were beneficial for them, as 75.0% agreed with the statement. The follow-up bereavement calls are made every few months to those “high risk” individuals, and 82.9% of those who responded felt the calls were beneficial to them. Only 18 and 20 participants said they participated in the support group or counseling option, respectively, but the majority of those participants felt the experience was beneficial for them. More publicizing of these grief/bereavement options

may need to be done as the majority of those who participated in the options, or at least those who said they participated, responded that they benefited from them.

### **C. Summary of Qualitative Data**

Common themes in what participants found most helpful about the hospice care they received were the availability of a nurse 24-hours per day through the on-call system, knowing they were there and willing to come if needed, answering their questions day or night, providing needed and helpful information, and being attentive, responsive, supportive, and, a very common response was “they were wonderful”. Several people felt they were better prepared to care for their loved one at home with the assistance of hospice and their helpful explanations and suggestions. Two primary benefits the families of terminally ill patients from this home hospice program received were information and 24-hour availability.

Ironically, a common response to what participants found least helpful about the hospice care was “nothing”. One of the most common responses, although one specific response did not stand out as the most common, was that the home health aides from the contracted home care agency were the least helpful as they were unreliable or ineffective. This was also a common statement made under suggestions for improvements to the program. Another somewhat common response was that some people felt they could have benefited from more explanation and preparation for the dying process and what they could expect. This was also suggested under improvements, along with providing written information about the dying process. There is a pamphlet on the dying process available through the hospice program, and these suggestions may indicate that it needs to be offered and more readily available to families.

#### **D. Limitations**

##### Generalizability:

A convenience sample was obtained for this research study, which used participants from one particular hospice program in the Twin Cities area. Although the sample size was significant at 128 participants, and the response rate was quite high at 64%, the participants all received hospice care from this particular hospice program. Its generalizability to other hospice programs in the area and to the hospice philosophy as a whole may be limited. This study also limited the sample to those primary care persons whose loved one received hospice care and died during a six month period, between February, 1996 and July, 1996. This was done to limit the sample to a manageable size, to be able to get an idea of where participants were at in their bereavement process at the time of the study, and also cautioned against having the death occur too long ago that their memories of the care received could have faded. Its generalizability to those who received hospice care either before or after that time-frame may also be limited.

Another limitation in this study's generalizability is that it is impossible to determine whether or not it is generalizable to ethnic populations. The questionnaire did ask participants to respond, if applicable, to whether or not hospice was sensitive to varying cultural, spiritual, ethnic and language needs. However, only 39 out of 82 participants responded to this question and it is impossible to determine which aspect of the question they were responding to and was applicable to them. A substantial 82% of those who responded felt hospice was sensitive to these needs. The questionnaire did not ask participants to provide their racial or ethnic background. It is the experience of this author that the program does not serve a very diverse population, as most of the people



served tend to be Caucasian and middle to upper-class individuals. It is an area not addressed in this study but would be an interesting topic of research.

Another area this research study does not address is the specific disease of each patient. It is impossible to know if they were primarily cancer patients or if they suffered from diverse illnesses. The literature review done for this study discusses the unique needs and characteristics of several different terminal illnesses. The generalizability of the results to all illnesses cannot be determined as the disease each patient suffered from is unknown.

#### Instrument Design:

The data collection tool used for this research study has some disadvantages that need to be considered as possible limitations to this study. Some participants answered the majority of questions but left some items blank. It is possible that they left some unanswered because they did not understand what was being asked. It is also possible that some participants did not understand the question but answered anyway, which could produce a false response from the participants.

Also, the category “not applicable” was added for two questions as they referred to care received in the home and not everyone was cared for in the home. It was intentionally not an option for all questions so people would not overuse that response if they were unsure or it was a difficult question to answer. However, several participants added it as a category for several other questions and said “not applicable” even though that was not one of the response categories. This could also skew some of the results.

To avoid an acquiescent response by participants of getting into a habit or pattern of answering in one particular way, questions posed in both negative and positive ways

were interspersed throughout the questionnaire. This may have been confusing for some participants and possibly made the questionnaire difficult to read. In a few instances, the principal investigator questioned whether or not the participant understood or read the question correctly, as they circled agree or strongly agree that hospice was ineffective in assisting them to cope with the changing mental capacity of their loved one, but then wrote a comment about how helpful they were in this regard. They possibly read over the question quickly and read “effective” instead of “ineffective”, but there is no way to be certain of this.

Although a high response rate of 64% was received, one cannot account for those who chose not to return the questionnaire. Many precautions were taken to allow for complete anonymity of participants, but it is possible that those who may have had a negative experience with hospice did not feel comfortable completing and returning the questionnaire. Both quantitative and qualitative data were utilized in this research study to attempt to compensate for the disadvantages of using one method over the other and to obtain greater detail from participants.

#### Social Desirability and Researcher’s Bias:

Despite specific attention given to protect their anonymity and assure participants that their responses were completely anonymous, it is possible that some people responded favorably by nature despite their true feelings. Some individuals may not have felt comfortable being completely honest on the questionnaire as having one’s feelings on paper may seem threatening.

The researcher for this study, after interning in hospice care and doing extensive research on the topic, has a strong bias in support for the use of hospice care for

terminally ill patients and their family members. This bias may have possibly skewed the development of the questionnaire to promote positive responses or the interpretation of the findings to emphasize positive responses. However, the researcher was cognizant of this bias and showed all responses in the statistical analysis.

Lack of a Control Group:

A significant limitation to this study is a lack of a control group. This study questioned only those primary care persons of terminally ill patients who did receive the services of hospice care and sought to discover what benefits that care provided the family members. A control group of family members of terminally ill patients who did not receive hospice care could have been used to determine if indeed hospice care is rated higher than conventional care. Some research indicates that families do voice greater satisfaction with care provided by a hospice program than any other form of care (Dawson, 1991; Seale, 1991), but without a control group this study cannot address that point. The use of a control group would have strengthened the results of this study and made it a more complete and significant research study.

Despite these limitations, this research study had a significantly high response rate and yielded some valuable information for the hospice program on how their services are viewed by recipients of the care and provided them with some helpful suggestions for improvements to their program to make it grow and become an even stronger program.

## **VII. Implications and Recommendations**

### **A. Implications for Practice**

The diagnosis of a terminal illness within the family is a very traumatic, stressful event that changes the entire family system from that point forward. Terminally ill patients and their families are greatly impacted and have many needs during this most stressful time. Research indicates that the use of hospice care can be beneficial for these patients and their families as it can assist them in meeting some of their needs, provide support and guidance, and also provide bereavement follow-up after the death. Research also indicates that these services can also help to make the bereavement process easier for these families.

The results of this research study support previous research as participants rated the assistance of the hospice staff highly, offered many positive comments about the care received, and overall rated hospice care beneficial to them at this time in their lives. A comment that was made more than once was “We could not have done it without the assistance of hospice care”. The majority of participants also stated their grief before the death, immediately following the death, and six to twelve months later in their bereavement process was less with the assistance of the hospice team.

The results of this study provide support for the use of hospice care for terminally ill patients and their families. Key needs of family members were identified through the literature review and the results show that hospice care can assist families in meeting these needs. The results of the section on grief/ bereavement options along with the questions regarding the grief of the participants and some comments made in the

qualitative section can all provide valuable information for grief counselors. The findings can help counselors to better assist these grieving families.

The results of the qualitative data also yield several valuable suggestions for improvements to this hospice program on how it may better help the families meet their needs. The findings provide what participants found most helpful so the program knows what to continue doing, along with what they found least helpful so it can be aware of areas that may need improvement. Specific suggestions and recommendations were also made to provide the hospice program with some ideas for services to develop or strengthen in the future. Some of the main suggestions which may provide implications for practice were to improve the quality of the staff provided by the contracted home health care agency, and provide more explanations about the dying process and what to expect, including written material for their reference. Overall, the responses were very positive and support that the hospice program does a good job at assisting terminally ill patients and their families and should continue to do the excellent work.

### **B. Recommendations for Future Research**

Future research could conduct a similar study with a more diverse population with regard to the specific diseases of the patients along with cultural and ethnic diversity. Again, this study did not ask participants about their ethnic background or to specify the disease of the patients, but that would be interesting and valuable data to obtain to strengthen the knowledge base on hospice care. Replication of the study can be effective in providing further support and evidence of the benefits hospice provides to terminally ill patients and their families. Also, a study conducting a comparison of more than one hospice program would have greater generalizability to the hospice philosophy.

Further research could also better address the question of whether or not hospice care can be effective in easing the bereavement process of family members. Another research study could focus questions more specifically on the grief and bereavement of the family members. This study only scratched the surface on the idea that the assistance of hospice care can help ease some of the bereavement process for family members of terminally ill patients. This is extremely valuable information for hospice care providers and grief counselors, and more research is needed to provide support and evidence for this relatively new concept.

The initiation of a similar study with a control group of participants who did not receive hospice care when their family member was terminally ill is needed. A comparison of conventional care and hospice care should be done to clearly define if hospice is viewed as more beneficial and satisfying to patients and family members than conventional care. The results of this study support that participants felt hospice care was beneficial for them and assisted them in meeting some of their needs, but a control group was not used to discover if the recipients of hospice care were more satisfied with services than recipients of conventional care. The results of a study with a control group could more significantly address the benefits hospice can provide family members.

This research study was considered exploratory in nature and sought to discover overall benefits hospice can provide to its patients and families. The results obtained do support the use of hospice care and provided valuable information for the hospice program. Further research on this topic needs to be done to continue the growth and awareness of the use of hospice care for terminally ill patients and their families.

## VIII. Conclusion

The advancements in medicine and technology over the past several decades have given people with a terminal or chronic illness some choices about the location of their care. When these people choose to be cared for at home, there needs to be a family member or close friend available to provide that care. The hospice movement grew out of a need to support and provide assistance to these caregivers, to promote a humane way of caring for terminally ill patients, and to respond to the changing needs of an aging society. The use of hospice care has grown steadily since its inception in the late 1960s and provides care in a variety of settings in addition to the patient's home.

Research has begun to suggest that hospice can assist families in meeting some of their needs and possibly ease some of their bereavement process by providing support and guidance throughout the terminal illness and for several months after the death. The purpose of this research study was to explore what benefits hospice care provides the families of terminally ill patients, with some questions on the self-administered questionnaire referencing their grief and bereavement process.

The results of this research study help support the growth of the hospice movement as participants rated the services of hospice as significantly beneficial to them and assisted them in getting through a very difficult time in their lives. The results also suggest that hospice may indeed assist families with some of their bereavement as participants responded favorably that their grief before the death, immediately following it and several months later was less due to the assistance of hospice care. Further research needs to be conducted to continue to support the growth of the hospice

movement across the United States and to increase its awareness so the services of hospice care can be expanded to help more terminally ill patients die with dignity, their pain and symptoms managed, and the comfort of knowing their families will be supported.



## References

- Austrom, M. G., & Hendrie, H. C. (1992). Quality of life: The family and Alzheimer's Disease. Journal of Palliative Care, 8(3), 56-60.
- Berardo, D. H., & Berardo, F. M. (1992). Quality of life across age and family stage. Journal of Palliative Care, 8(3), 52-55.
- Bissell, H. G. (1992). Reviewing life strategy in the approach to death. Social Work, 37(4), 374-375.
- Davidson, G. W. (ed.). (1985). The hospice: Development and administration (2nd ed.). New York: Hemisphere Publishing Corporation.
- Dawson, N. J. (1991). Need satisfaction in terminal care settings. Social Science & Medicine, 32(1), 83-87.
- Duhatschek - Krause, A. L. (1989). A support group for patients and families facing life-threatening illness: Finding a solution to non-being. Social Work With Groups, 12(1), 55-69.
- Eisdorfer, C., Kessler, D. A., & Spector, A. N. (eds.). (1989). Caring for the elderly: Reshaping health policy. Baltimore, Maryland: The Johns Hopkins University Press.
- Etten, M. J., & Kosberg, J. I. (1989). The hospice caregiver assessment: A study of a case management tool for professional assistance. The Gerontologist, 29(1), 128-131.

- Folkman, S., Chesney, M., Collette, L., Boccillari, A., & Cooke, M. (1996). Postbereavement depressive mood and its prebereavement predictors in HIV+ and HIV-gay men. Journal of Personality and Social Psychology, 70 (2), 336-348.
- Freese, A. S. (1977). Help for your grief. New York: Schocken Books.
- Fulton, R., & Bendiksen, R. (eds.). (1994). Death & identity (3rd ed.). Philadelphia, PA: The Charles Press, Publishers, Inc.
- Gardner, K. (ed.). (1985). Quality of care for the terminally ill: An examination of the issues. Chicago, Illinois: Joint Commission on Accreditation of Hospitals.
- Gordon, A. K. (1995). Deterrents to access and service for blacks and Hispanics: The Medicare Hospice Benefit, healthcare utilization, and cultural barriers. The Hospice Journal, 10 (2), 65-83.
- Guilfoyle, B. A. (1992). Physicians and social workers: Perspectives on collaboration during the terminal care phase. Loss, Grief and Care, 6 (2-3), 23-25.
- Halfe, L. B. (1989). The circle: Death and dying from a native perspective. Journal of Palliative Care, 5 (1), 37-41.
- Hanrahan, P., & Luchins, D. J. (1995). Feasible criteria for enrolling end-stage dementia patients in home hospice care. The Hospice Journal, 10 (3), 47-54.
- Huber, R., & Gibson, J. W. (1990). New evidence for anticipatory grief. The Hospice Journal, 6 (1), 49-67.
- Infeld, D. L., Crum, G. E., & Koshuta, M. A. (1991). Characteristics of patients in a long-term care hospice setting. The Hospice Journal, 6 (4), 81-104.

Irish, D. P., Lundquist, K. F., & Jenkins Nelsen, V. (eds.). (1993). Ethnic variations in dying, death, and grief: Diversity in universality. Washington, DC: Taylor & Francis.

Jimenez, M. A., & Jimenez, D. R. (1990). Training volunteer caregivers of persons with AIDS. Social Work in Health Care, 14 (3), 73-85.

Kastenbaum, R. J. (1995). Death, society, and human experience (5th ed.). Neeham Heights, Mass.: Allyn and Bacon.

Katz, J., & Sidell, M. (1994). Easeful death: Caring for dying and bereaved people. London: Hodder & Stoughton.

Kaye, L. W., & Davitt, J. K. (1995). Provider and consumer profiles of traditional and high-tech home health care: The issue of differential access. Health and Social Work, 20 (4), 262-271.

Kinzel, T. (1992). End-stage lung disease: A hospice approach to the psychosocial aspects of care. Loss, Grief and Care, 6 (2-3), 137-146.

Kirschling, J. M. (1989). Analysis of Bugen's model of grief. The Hospice Journal, 5 (1), 55-75.

Knapp, E. R., & Delcampo, R. L. (1995). Developing family care plans: A systems perspective for helping hospice families. The American Journal of Hospice & Palliative Care, 12 (6), 39-47.

Kramer, D. (1992). How women relate to their terminally ill husbands and their subsequent adjustment to bereavement. Ann Arbor, Michigan: UMI Dissertation Services.

Kristjanson, L. J. (1989). Quality of terminal care: Salient indicators identified by families. Journal of Palliative Care, 5(1), 21-30.

Kulys, R., & Davis, M. A. (1986). An analysis of social services in hospices. Social Work, 31 (6), 448-456.

Leick, N., & Davidsen-Nielsen, M. (1991). Healing pain: Attachment, loss and grief therapy. New York: Tavistock/Routledge.

Lerman, D., & Tehan, C. (eds.). (1995). Hospital-hospice management models: Integration and collaboration. Chicago, Illinois: American Hospital Publishing, Inc.

Luchins, D. J., & Hanrahan, P. (1993). What is appropriate health care for end-stage dementia? Journal of the American Geriatrics Society, 41 (1), 25-30.

MacDonald, D. (1991). Hospice social work: A search for identity. Health and Social Work, 16 (4), 274-280.

MacLean, M. J., & Sakadakis, V. (1989). Quality of life in terminal care with institutionalized ethnic elderly people. International Social Work, 32 (3), 209-221.

Magno, J. B. (1990). The hospice concept of care: Facing the 1990s. Death Studies, 14 (2), 109-119.

Martin, J. P. (1986). Ensuring quality hospice care for the person with AIDS. Quality Review Bulletin, 12(10), 353-358.

Martin, J. P. (1988). Hospice and home care for persons with AIDS/ARC: Meeting the challenges and ensuring quality. Death Studies, 12 (5/6), 463-480.

McCann, B. A. (1985). The hospice project report. Chicago, Illinois: Joint Commission on Accreditation of Hospitals.

- McCracken, A. L., & Gerdson, L. (1991). Sharing the legacy: Hospice care principles for terminally ill elders. Journal of Gerontological Nursing, 17 (12), 4-8.
- McNeil, J. S. (1995). Bereavement and loss. In Encyclopedia of Social Work (Vol. 19, pp. 284-291). Washington, DC: National Association of Social Workers.
- McWhinney, I. R. (1989). Family dynamics in the achievement of symptom control. Journal of Palliative Care, 5 (2), 37-39.
- Mor, V., Greer, D. S., & Kastenbaum, R. (eds.). (1988). The hospice experiment. Baltimore, Maryland: The Johns Hopkins University Press.
- Munley, A. (1983). The hospice alternative: A new context for death and dying. New York: Basic Books, Inc.
- Noggle, B. J. (1995). Identifying and meeting needs of ethnic minority patients. The Hospice Journal, 10 (2), 85-93.
- Norris, F. H., & Murrell, S. A. (1987). Older adult family stress and adaptation before and after bereavement. Journal of Gerontology, 42 (6), 606-612.
- Rando, T. A. (1984). Grief, dying, and death: Clinical interventions for caregivers. Champaign, Ill: Research Press Company.
- Rando, T. A. (1986). Loss and anticipatory grief. Lexington, Mass.: D.C. Health and Company.
- Remsen, M. F. (1993). The role of the nursing home social worker in terminal care. Journal of Gerontological Social Work, 19 (3-4), 193-205.
- Richman J. M. (1990). Groupwork in a hospice setting. Social Work With Groups, 12 (4), 171-184.

Rosen, E. J. (1987). Teaching family therapy concepts to the hospice team. The American Journal of Hospice Care, 4 (4), 39-48.

Rusnack, B., & Schaefer, S. M., & Moxley, D. (1991). Hospice: Social work's response to a new form of social caring. Social Work in Health Care, 15 (2), 95-119.

Sable, P. (1992). Attachment, loss of spouse, and disordered mourning. Families in Society: The Journal of Contemporary Human Services, 73 (5), 266-273.

Schachter, S. (1992). Quality of life for families in the management of home care patients with advanced cancer. Journal of Palliative Care, 8 (3), 61-66.

Schoenberg, B. M. (ed.). (1980). Bereavement counseling: A multidisciplinary handbook. Westport, Conn.: Greenwood Press.

Seale, C. (1991). A comparison of hospice and conventional care. Social Science & Medicine, 32 (2), 147-152.

Sonnenblick, M., Friedlander, Y., & Steinberg, A. (1993). Dissociation between the wishes of terminally ill parents and decisions by their offspring. Journal of the American Geriatrics Society, 41 (6), 599-604.

Stroebe, W., & Stroebe, M. S. (1987). Bereavement and health: The psychological and physical consequences of partner loss. New York: Cambridge University Press.

Suszycki, L. H., Abramson, M., Prichard, E., Kutscher, A. H., & Fisher, D. (eds.). (1984). Social work and terminal care. New York: Praeger Publishers.

Torrens, P. R. (ed.). (1985). Hospice programs and public policy. New York: American Hospital Publishing, Inc.

Vachon, M. L. S., Kristjanson, L., & Higginson, I. (1995). Psychosocial issues in palliative care: The patient, the family, and the process and outcome of care. Journal of Pain and Symptom Management, 10 (2), 142-149.

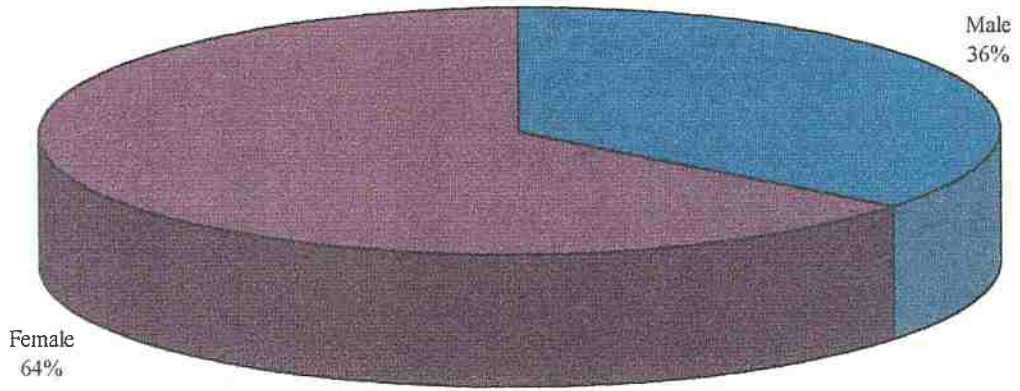
vanWormer, K. (1990). Private practice with the terminally ill. Journal of Independent Social Work, 5 (1), 23-37.

Weir, R. F. (1989). Abating treatment with critically ill patients: Ethical and legal limits to the medical prolongation of life. New York: Oxford University Press.

Worden, J. W. (1991). Grief counseling and grief therapy: A handbook for the mental health practitioner. New York: Springer Publishing Company.

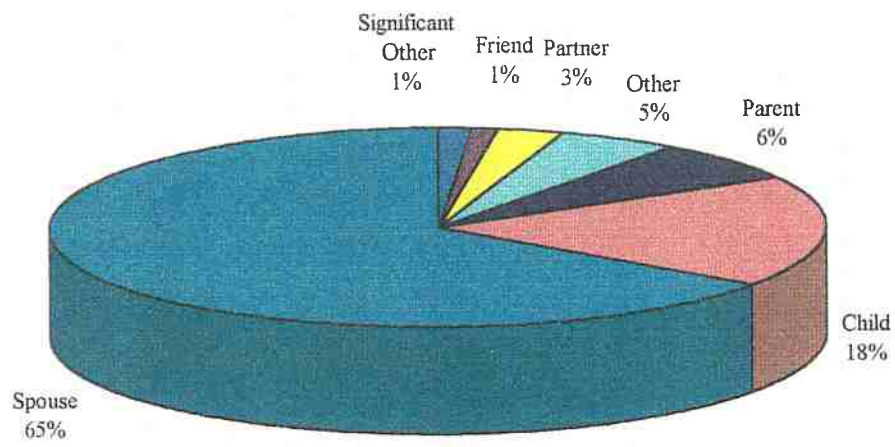
Zweibel, N. R., & Cassel, C. K. (1989). Treatment choices at the end of life: A comparison of decisions by older patients and their physician-selected proxies. The Gerontologist, 29 (5), 615-621.

**Graph #1**

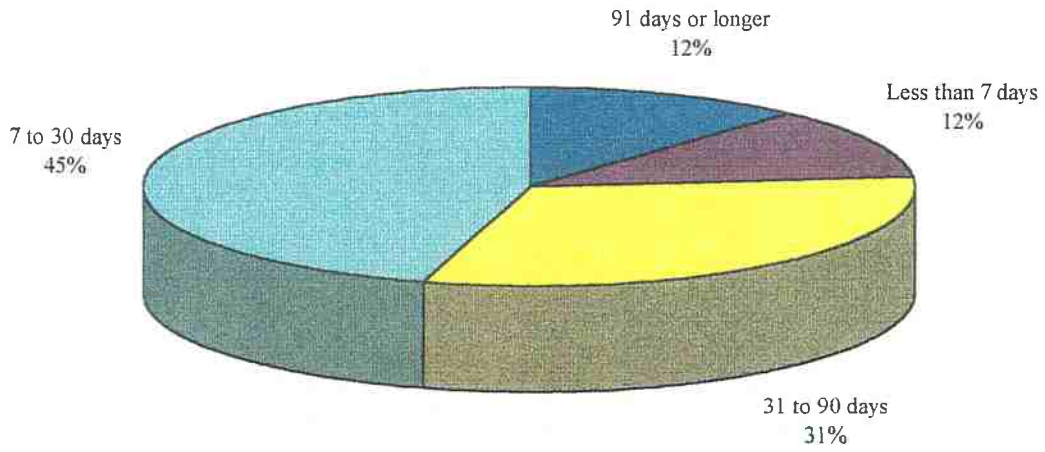




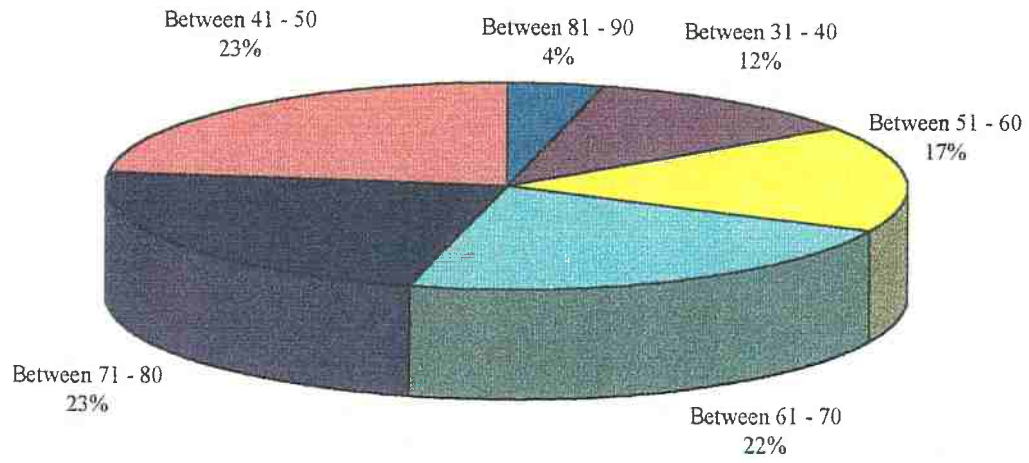
Graph #2



**Graph #3**



**Graph #4**



# **Appendix A**

November 25, 1996

Rita Weisbrod, PHD  
Institutional Review Chairperson  
Augsburg College #186  
2211 Riverside Avenue  
Minneapolis, MN 55454-1351

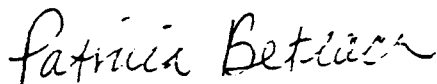
RE: Karen Cartwright, MSW Intern

Dear Dr. Weisbrod:


We are writing to you on behalf of Karen Cartwright, MSW graduate student at Augsburg College. Karen is completing her field placement in our home hospice program. She will be conducting a research study at Home Hospice program. We know this research will be a valuable source of information for our hospice team, and we give Karen our enthusiastic support and thanks for choosing this topic.

Karen has our permission to use medical records of patients and families participating in the study. She has been informed of our confidentiality policy and has been practicing under it during her internship.

Sincerely,



Patricia Betlach  
Director of Patient Services - Community Care  
Home Care and Hospice



Carol O'Brien, LICSW  
Hospice Social Worker

PB/CO/gh  
IA...HCHSPCARTWLTR

# **Appendix B**

February 21, 1997

Dear Primary Care Persons,

I am a graduate student working toward a Masters in Social Work degree at Augsburg College in Minneapolis, MN. I am also an intern at the [name of hospital] Hospice Program. For my thesis, I am researching the needs of family members of patients with a terminal illness and exploring how hospice care can assist them in meeting those needs and help ease their bereavement process. You were selected as a possible participant because you were the primary care person of a patient who was enrolled in the [name of hospital] Hospice Program and passed away between six months and one year ago. This research study has been approved by and is being done in cooperation with the [name of hospital] Hospice Program. I ask that you please read this form very carefully.

#### BACKGROUND INFORMATION:

This research study is being conducted to provide me with information for my Master of Social Work thesis and to provide you with an opportunity to report your perceptions of the care provided to you and your loved one by the hospice team at [name of hospital] Hospital.

#### VOLUNTARY NATURE OF THIS STUDY:

Your experiences and opinions are important and could help others in the future who may require the assistance of hospice care. It is up to you whether or not to participate in this research study. I will not know whether or not you choose to participate in this study. A volunteer at [name of hospital] Hospital will know through a coding system if you return the questionnaire so that you do not receive a second mailing. However, no one at [name of hospital], including the volunteer, will have access to the questionnaire. Your decision will not affect your current or future relations with [name of hospital] Hospital or Augsburg College.

#### PROCEDURES AND ANONYMITY:

I am surveying the primary care persons of patients who were enrolled in the [name of hospital] Hospice Program and passed away between six months and one year ago. Your anonymity is protected as the [name of hospital] Hospice Program is mailing out this questionnaire. I do not know your name, nor will I have worked directly with you or your loved one. **I ask that you do not place any identifying information about yourself or the patient on this questionnaire or on the return envelope to ensure your anonymity.** Completed and returned questionnaires will be filed in a locked drawer at the principal investigator's home, will not become a part of medical records, and will be destroyed by August 30, 1997. Information from this questionnaire will be used for my thesis and any other reports, and will be shared with the hospice team at [name of hospital] Hospital in summarized form only.

### **RISKS OF BEING A PARTICIPANT IN THIS STUDY:**

By completing this questionnaire you may be reminded of some feelings or experiences associated with this difficult time in your life when hospice care was received. You may choose to skip any questions that are uncomfortable for you to answer without necessarily dropping out of this research study. In the event that this questionnaire produces emotional distress for you, please contact the [name of hospital] Hospice Program at [number], so you can receive assistance from the bereavement team, or attend the support group offered every Thursday evening at 6:30 in the cancer center at [name of hospital] Hospital for anyone who has suffered a loss.

### **BENEFITS OF BEING A PARTICIPANT IN THIS STUDY:**

While there are not direct benefits to you for participating in this research study, this is an opportunity for you to report your thoughts and own experiences with the hospice care you received through [name of hospital] which may, in turn, assist the hospital in assessing the services it provides to terminally ill patients and their family members, and may benefit others who require the services of hospice care in the future.

Will you please help in this research study by completing this questionnaire. This questionnaire is a one-time commitment on your behalf and may take you approximately twenty (20) minutes to complete. Once completed, please return this questionnaire in the enclosed self-addressed, stamped envelope as soon as possible and no later than March 7, 1997. The completion and return of this questionnaire will indicate your consent to participate in this research study as well as conclude your role in this study.

Thank you in advance for considering this research study. In two weeks, individuals who have not returned the questionnaire will receive a follow-up letter with an identical questionnaire requesting their participation in this study.

If you have any questions regarding this research study, please feel free to contact Carol O'Brien, LICSW, my supervisor at the [name of hospital] Hospice Program, at [number] or Sharon Patten, Ph.D., my thesis advisor at Augsburg College, at [number].

**Please keep this copy for your records.**

Thank you!

Sincerely,

Karen S. Cartwright  
Graduate Student and Principal Investigator



# Appendix C

March 10, 1997

Dear Primary Care Persons,

I am a graduate student working toward a Masters in Social Work degree at Augsburg College in Minneapolis, MN. I am also an intern at the [name of hospital] Hospice Program. A couple of weeks ago, [name of hospital] Hospital mailed you a letter regarding my thesis and my research surrounding the needs of family members of terminally ill patients. This second mailing is going out to those individuals who have not returned the questionnaire. If you have returned the questionnaire and they have possibly crossed in the mail, or you have decided not to participate in this study, please disregard this follow-up letter requesting your participation in this study. This research study has been approved by and is being done in cooperation with the [name of hospital] Hospice Program. I ask that you please read this form very carefully.

**BACKGROUND INFORMATION:**

This research study is being conducted to provide me with information for my Master of Social Work thesis and to provide you with an opportunity to report your perceptions of the care provided to you and your loved one by the hospice team at [name of hospital] Hospital.

**VOLUNTARY NATURE OF THIS STUDY:**

Your experiences and opinions are important and could help others in the future who may require the assistance of hospice care. It is up to you whether or not to participate in this research study. I will not know whether or not you choose to participate in this study. Your decision will not affect your current or future relations with [name of hospital] Hospital or Augsburg College.

**PROCEDURES AND ANONYMITY:**

I am surveying the primary care persons of patients who were enrolled in the [name of hospital] Hospice Program and passed away between six months and one year ago. Your anonymity is protected as the [name of hospital] Hospice Program is mailing out this questionnaire. I do not know your name, nor will I have worked directly with you or your loved one. **I ask that you do not place any identifying information about yourself or the patient on this questionnaire or on the return envelope to ensure your anonymity.**

Completed and returned questionnaires will be filed in a locked drawer at the principal investigator's home, will not become a part of medical records, and will be destroyed by August 30, 1997. Information from this questionnaire will be used for my thesis and any other reports, and will be shared with the hospice team at [name of hospital] Hospital in summarized form only.

**RISKS OF BEING A PARTICIPANT IN THIS STUDY:**

By completing this questionnaire you may be reminded of some feelings or experiences associated with this difficult time in your life when hospice care was received. You may choose to skip any questions that are uncomfortable for you to answer without necessarily dropping out of this research study. In the event that this questionnaire produces emotional distress for you, please contact the [name of hospital] Hospice Program at [number], so you can receive assistance from the bereavement team, or attend the support group offered every Thursday evening at 6:30 in the cancer center at [name of hospital] Hospital for anyone who has suffered a loss.

**BENEFITS OF BEING A PARTICIPANT IN THIS STUDY:**

While there are no direct benefits to you for participating in this research study, this is an opportunity for you to report your thoughts and own experiences with the hospice care you received through [name of hospital] which may, in turn, assist the hospital in assessing the services it provides to terminally ill patients and their family members, and may benefit others who require the services of hospice care in the future.

Will you please help in this research study by completing this questionnaire. This questionnaire is a one-time commitment on your behalf and may take you approximately twenty (20) minutes to complete. Once completed, please return this questionnaire in the enclosed self-addressed, stamped envelope as soon as possible and no later than March 24, 1997. The completion and return of this questionnaire will indicate your consent to participate in this research study as well as conclude your role in this study.

Thank you in advance for reconsidering this research study. If you have any questions regarding this study, please feel free to contact Carol O'Brien, LICSW, my supervisor at the [name of hospital] Hospice Program, at [number] or Sharon Patten, Ph.D., my thesis advisor at Augsburg College, at [number].

**Please keep this copy for your records.**

Thank You!

Sincerely,

Karen S. Cartwright  
Graduate Student and Principal Investigator

# **Appendix D**

**The Utilization of Hospice Care In Assisting  
To Meet The Needs of  
Family Members of Terminally Ill Patients**

**Instructions**

**\*\* If you did not stay with, or in close proximity to the hospice patient and assist with his/her care, please return this questionnaire unanswered in the enclosed self-addressed, stamped envelope. \*\***

**\*\* If you were the primary care person for the patient and participated in his/her care, please complete and return this questionnaire. PLEASE DO NOT WRITE YOUR NAME OR THE NAME OF THE PATIENT WHO RECEIVED HOSPICE CARE, OR PROVIDE ANY OTHER IDENTIFYING INFORMATION ON THIS SURVEY OR ON THE RETURN ENVELOPE. \*\***

Most of the questions on this questionnaire can be answered simply by circling a response that best reflects your perspective. For example, questions can be answered by circling ONE of a series of numbers such as:

(SD)	(D)	(U)	(A)	(SA)
1	2	3	4	5

If you **strongly disagree** with the statement, please circle the number 1.

If you **disagree** with the statement, please circle the number 2.

If you are **not sure** of an answer or are **undecided** about the statement, please circle the number 3.

If you **agree** with the statement, please circle the number 4.

If you **strongly agree** with the statement, please circle the number 5.

This questionnaire is organized into two sections related to the needs of family members of terminally ill patients. At the end of each section, please add any comments or suggestions.

Your experiences and opinions are important!  
Your assistance with this questionnaire may help the hospital assess the services it provides to hospice patients and may, in turn, assist others in the future who require the assistance of hospice care.

**Thank you in advance for considering this research study!**

# **Appendix E**

Please circle the ONE best answer for each question, then provide your comments and suggestions at the end of each section. This may take you approximately twenty (20) minutes. Thank you very much.

- Scale:           1= Strongly Disagree  
                       2= Disagree  
                       3= Undecided  
                       4= Agree  
                       5= Strongly Agree

<b>A. Medical/Physical Needs:</b>	<b>SD</b>	<b>D</b>	<b>U</b>	<b>A</b>	<b>SA</b>	<b>NA</b>
1. Hospice assisted in providing me with the knowledge and skills necessary to care for my loved one at home. If this question does not apply to your situation, please circle #8.	1	2	3	4	5	8
2. Before hospice became involved, I had difficulty obtaining necessary information from my health care professionals.	1	2	3	4	5	
3. The hospice team aided me in obtaining necessary information regarding the disease and physical needs of my loved one.	1	2	3	4	5	
4. The hospice team lacked the ability to diminish the demands placed on me in the care of my loved one.	1	2	3	4	5	
5. Hospice offered trained staff to provide me with a break, or time away when I needed it.	1	2	3	4	5	
6. The trained staff also enabled me to get some rest, so I was less physically exhausted than I feel I would have been without hospice.	1	2	3	4	5	
7. I had difficulty obtaining the medical equipment necessary to care for my loved one at home. If this question does not apply to your situation, please circle #8.	1	2	3	4	5	8
8. The hospice staff explained the physical changes I might see in my loved one as he/she approached death, which helped to prepare me for his/her final days.	1	2	3	4	5	

	<b>SD</b>	<b>D</b>	<b>U</b>	<b>A</b>	<b>SA</b>
9. Hospice could have kept me better informed about my loved one's condition during his/her decline.	1	2	3	4	5
10. I feel the hospice team was dishonest with me at times.	1	2	3	4	5
11. I felt comfortable and able to have open communication with the hospice team regarding my loved one's condition.	1	2	3	4	5

Please add any comments/suggestions you may have regarding the assistance of the [name of hospital] hospice team in meeting the medical and physical needs of you and your loved one:

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**B. Emotional Needs:**

	<b>SD</b>	<b>D</b>	<b>U</b>	<b>A</b>	<b>SA</b>
1. Hospice was ineffective in assisting me to cope with my loved one's changing mental capacity.	1	2	3	4	5
2. Hospice aided me in coping with my loved one's changing physical condition.	1	2	3	4	5
3. The hospice staff could have offered more opportunity to discuss my fears and concerns.	1	2	3	4	5
4. I feel the hospice team helped me work through some of the grief before the death occurred.	1	2	3	4	5
5. I feel my grief immediately following the loss was less than it would have been had we not received hospice care.	1	2	3	4	5
6. I feel my grief today is less than it would have been had we not received hospice care.	1	2	3	4	5
7. I wanted my loved one to remain at home until his/her death.	1	2	3	4	5
8. Hospice worked hard to attempt to make the above ( #7 ) possible.	1	2	3	4	5



9. Below are listed the grief/bereavement options offered by [name of hospital]. For those in which you participated, please rate according to the following statement:  
I feel this grief/bereavement option was beneficial for me.

	<b>SD</b>	<b>D</b>	<b>U</b>	<b>A</b>	<b>SA</b>
letters/mailings	1	2	3	4	5
bereavement calls	1	2	3	4	5
grief classes	1	2	3	4	5
support group	1	2	3	4	5
counseling	1	2	3	4	5

**If applicable, please respond:**

10. Hospice was sensitive to varying cultural, spiritual, ethnic and language needs. 1 2 3 4 5

Please add any comments/suggestions regarding the use of hospice care in meeting the emotional needs of you and your loved one during this most difficult time:

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Please list what you found most helpful about the hospice care you received during your loved one's final days:

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Please list what you found least helpful about the hospice care:

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If you were to suggest any changes to the [name of hospital] Hospice Program, what would they be?

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**C. Background Information - Please circle one:**

1. What is your sex?
  - (1) Female
  - (2) Male
  
2. What was your relationship to the patient?
  - (1) Spouse
  - (2) Child
  - (3) Parent
  - (4) Partner
  - (5) Significant Other
  - (6) Friend
  - (7) Other (please specify: \_\_\_\_\_)
  
3. How long was your loved one enrolled in hospice care?
  - (1) Less than 7 days
  - (2) 7 to 30 days
  - (3) 31 to 90 days
  - (4) 91 days or longer
  
4. What is your age?

(1) Between 18-30	(5) Between 61-70
(2) Between 31-40	(6) Between 71-80
(3) Between 41-50	(7) Between 81-90
(4) Between 51-60	(8) 91 or older

**Thank You Very Much For Your Participation In This Research Study!**

