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A Community Wide Study Of The Hospice Referral Process

Jarilyn K. Gess

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A COMMUNITY WIDE STUDY OF THE
HOSPICE REFERRAL PROCESS

by

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A Dissertation
Submitted to the Graduate Faculty
of the
University of North Dakota
in partial fulfillment of the requirements
for the degree of
Doctor of Philosophy

Grand Forks, North Dakota
May
1999
This dissertation, submitted by Jarilyn K. Gess in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

[Signatures]

This dissertation meets the standards for appearance, conforms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

[Signature]

Dean of the Graduate School

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Title A Community Wide Study of the Hospice Referral Process
Department Teaching and Learning
Degree Doctor of Philosophy

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ACKNOWLEDGMENTS

There are many persons who should be properly acknowledged for his/her contributions to my education. However, due to space limitations, my formal acknowledgments will include those persons who were central in my completion of my doctoral studies and individuals who made this study possible.

I wish to thank Dr. Jean Quam, Chair of the Department of Social Work, University of Minnesota, Dr. Richard DuBord, Chair of the Department of Social Work, Moorhead State University, and my colleagues in both Departments of Social Work who made it possible for me to pursue the degree. Their ongoing support made this endeavor a reality.

To my dissertation committee is owed special gratitude. Dr. John Delane Williams, advisor and chairperson, who skillfully guided the process. Dr. Myrna Olson, my mentor and friend, who struggled with me at each stage of my dissertation with acumen and expertise. A very special thank you for all of her support, thought filled suggestions, and continual encouragement. Drs. Janet Kelley Moen, Mary Ruth Laycock, and David Perry who were interested, diligent readers and able advisors. I also want to thank Sharon Fields for her skillful editing and friendship during my doctoral pursuit.

Dr. Daniel J. Klenow, who guided my thesis in 1990, is owed a special thank you for providing me with the opportunity to be the research associate for the study. His continued support, mentoring, and friendship are important to me.

Without the support of Susan Fuglie, Executive Director of Hospice of the Red River Valley, and the funded support of the Allina Foundation, Minneapolis, Minnesota, this study would not have been possible. A special thank you to Susan and all of the
hospice representatives who worked with me on the study, especially Judy Mortenson, who provided the names of participants to me and who explained the purpose of the study to each participant obtaining his/her consent to participate in the study.

I wish to especially thank each of the participants who completed the interview. Each shared his/her referral story in a thoughtful, heart filled manner, contributing the data for the study.

I want to thank my sister, Roselyn, and her husband, Dick, for all of their encouragement, support, and assistance. This dissertation is dedicated to my Grandmother Rose, whose unconditional love and support always taught me to value education and to persevere—to be a doctor and not to marry a doctor. A special thank you to my family who willingly accepted a major disruption of their lives as I completed this process. They were not only patient but also supportive, understanding, and loving throughout my doctoral studies.
You matter because of who you are,
You matter to the last moment of your life,
and we will do all we can,
not only to help you die peacefully,
but also to live until you die.

(Dame Cicely Saunders, Founder of the Modern Hospice Movement)
ABSTRACT

The purpose of this research study was to understand the decision making process when seeking hospice care. The objectives were to identify the decision maker for the patient when seeking hospice care, why they were seeking hospice care, who initiated the referral, if the decision maker was aware they can self refer to hospice care, and the benefits of hospice care for the patient and family.

The study is a qualitative and quantitative descriptive study utilizing a telephone survey design as described by Dillman (1978). One hundred patients who had been referred to Hospice of the Red River Valley (HRRV) between February 1998 and September 1998 were asked to identify the decision maker for participation in the study. All decision makers had an equal chance of participating in the study.

Findings from the study suggest that patients are referred to hospice by physicians most often (32%) with health care professionals suggesting hospice care to patients in 81% of the cases. Admission to hospice care was first considered within one week or less by 65% of the patients. The discussion was initiated by a physician (20%), the final decision to seek hospice care was made by the patient (41%), and the decision maker participating in the study most was a daughter (31%). Awareness of hospice is quite high as 96% of the participants reported having heard of hospice prior to his/her family member becoming ill. Reported benefits of hospice care included support, comfort care, volunteer visits, education, Medicare benefits, pain management, and symptom control, as well as being allowed to die at home. In addition, the 24 hour crisis care and bereavement follow-up were also mentioned as being of benefit to families. Barriers to hospice care included the admission criteria for Medicare as well as Medicare regulations, not understanding the
referral process, physicians not being supportive of hospice care, believing hospice was only available for persons with cancer, not knowing he/she was dying, and not understanding the criteria necessary for being hospice appropriate. Seventy-five percent of the participants did not know he/she could self refer.
CHAPTER I
INTRODUCTION

This study describes the referral process as it relates to the decision making process of those persons seeking hospice care. Hospice of the Red River Valley (HRRV) has experienced stagnant referrals to hospice care, and it appears that the average length of stay is also declining. In an effort to understand why, HRRV initiated a project in January 1998 receiving funds from the Allina Foundation, Minneapolis, Minnesota, to support the study. An anticipated data collection period of six to nine months was completed and reported herein.

The study was a community wide telephone survey utilizing the "total design method" as described by Dillman (1978). The perceived decision maker was the participant in the study. Non-probability sampling was the sampling technique used for the study so that each of the perceived decision makers had an equal opportunity of participating in the study. Hence, the sample was a census of perceived decision makers from February 1998 to September 1998, at which time 100 cases were realized. Findings are discussed qualitatively as participants shared their referral story. Data will also be presented descriptively as frequencies, which comes from a quantitative perspective.

Background of the Study

Hospice of the Red River Valley (HRRV) is a not-for-profit, self sustaining hospice organization providing care to the terminally ill and their families in their home or in a long term care (LTC) facility. The information reported in this section was provided by M. L. Dahms (personal communication, May 6, 1998), the Director of Public Relations and
Anyone with a terminal illness, having six months or less to live, if the disease follows the expected course, is appropriate for hospice care. HRRV is Medicare certified and eligible for reimbursement by most private insurance companies. HRRV celebrated its 15th year of providing services to the region in 1996. Since 1981, they have served 2,500 families.

A History of HRRV

On December 12, 1978, the first Board of Director's meeting of HRRV was held at Lutheran Social Services of North Dakota (LSSND). The Alex Stern Foundation provided the initial funding through a $5,231.00 grant. In early 1979, Bruce Briggs, then Executive Director of Minn-Dak, an area federal health planning agency, volunteered his services to provide direction for the development of HRRV. A formal purpose statement and goal were developed, a brochure was produced, and funding as well as financial support options were explored. By the end of 1979, a committee was formed to begin to develop a position description for a Nursing Coordinator for HRRV.

The American Lutheran Church provided an additional $8,000.00 and in September 1980 a search was initiated for a Nursing Coordinator. Edith M. Lohr was hired as the first Nursing Coordinator in March 1981. She was presented with a six month contract. Her contract was contingent on the availability of the continued resource funding necessary to maintain hospice services.

The first hospice offices were in a space donated by LSSND at 1325 11th Street South in Fargo, North Dakota. The first patient received hospice care in June 1981. By December 1981, HRRV had an average daily census of three patients with as many as eight patients being cared for at any one time. Lloyd Everson, Chief Oncologist at then St. Lukes Hospital (MeritCare) in Fargo, served as the first Medical Director for HRRV.
In 1983, HRRV was the first hospice program west of the Mississippi River to receive Medicare certification. On February 8, 1984, they were issued the first Medicare payment in the nation for coverage of hospice care. The check issued was in the amount of $9,653.63.

HRRV, by September 1984, had expanded all of its services to Cass County in North Dakota and Clay County in Minnesota. This expansion doubled its geographic service area. Blue Cross of North Dakota and HRRV entered into a one year agreement offering expanded home care benefits to the Blue Cross subscriber in 1985. This program provided patients with the option of home care instead of hospital care and was expanded to include Traill County. The expansion to Traill County demonstrated a cost savings of hospice home care for dying patients in a sparsely populated area.

Funding for the organization continues to be a challenge. The Alex Stern Foundation of Fargo-Moorhead, the Allina Foundation of Minneapolis, Minnesota, the Minneapolis based Otto Bremer Foundation, United Way of Cass Clay, the Clay County Welfare Board, the Cass County Commission, and the Fargo City Commission are some of the agencies that have provided funding to HRRV through the years. United Way efforts have provided them with over $400,000.00 of additional revenue since 1984. In 1986, the Annual Roger Maris Celebrity Golf Tournament began in the Fargo area after the diagnosis of Roger Maris' cancer. The Maris family determined that a portion of the proceeds from this annual event be given to HRRV. Total support realized from the golf tournament through 1996 to HRRV has exceeded $200,000.00 (Hospice, 1996).

HRRV began to expand its services to long term care (LTC) facilities in 1987. Villa Maria Nursing Home in Fargo was the first LTC facility to participate in the partnership. Sixteen facilities currently participate in providing hospice care to their patients and residents in North Dakota. Fourteen LTC facilities in Minnesota provide hospice care to their residents.
In 1989, HRRV moved to a larger location at 1316 23rd Street South in Fargo. In June 1990, a two story office building located at 702 28th Avenue North in Fargo was donated to the organization by five local businesses. A $300,000.00 fund drive was initiated to renovate the building, and in July 1992, HRRV staff moved into their current location in the donated building at 702 28th Avenue North. Presently, HRRV is seeking to expand to a new location having outgrown their current building.

Offices are located in Detroit Lakes and Thief River Falls in Minnesota; Fargo, Lisbon, Mayville, and Valley City in North Dakota servicing Barnes, Cass, Traill, Steele, Ransom, and a portion of Griggs counties in North Dakota. Counties served by HRRV in Minnesota include Becker, Clay, Mahnomen, Marshall, Norman, Pennington, and Red Lake (Appendix D).

Hospice of the Red River Valley has also expanded its bereavement follow-up services. Services provided include Kids and Teens Grieve, Too, Camp HOPE (Hospice Offers Positive Experiences), as well as Grief Journeys and Young Widows support groups. The support groups are also offered to individuals in the community not having been served by hospice services.

Rationale

As I reflect on my earliest experience with death and dying, I find myself developing a personal rationale for my interest in this study. I begin with the death of my biological father three days prior to my third birthday. This was the beginning of several familial losses before I graduated from high school. I found myself immersed in books related to death, dying, and loss. In an effort to understand "why," I continued to search for both book explanations as well as spiritual ones.

Before I graduated from high school, a good friend of mine was killed in an alcohol related automobile accident in Denver, Colorado. Graduation was fraught with doom. A chair was donned in a black sheet and the Valedictorian focused on what had happened
instead of celebrating what had been accomplished. Instead of a recognition celebration, we all shared in each other's grief. This experience, more than any other loss, was a turning point for me. There had to be a better way to cope with a person's death than to focus only on the sadness. I understand grief is a process and as a process I know it must be experienced for us to integrate the loss into the fabric of one's life—to find closure and acceptance of the experience. However, as I observed reactions of others, their coping styles, their definition of the event, the lack of social support systems and resources available to those in need, I only became more fascinated with death, dying, and loss. I have to admit, my passion was not shared by many, and I soon learned that this was a topic few wanted to discuss.

When I was a sophomore in college, I registered for a course at North Dakota State University (NDSU) that focused on death and dying, Sociology 441 (Sociology of Death and Dying). This course was taught by an instructor who would soon become one of my mentors, Dr. Daniel J. Klenow.

Eventually, I found myself registering for every special topic course related to death and dying available. Independent study courses were developed to assist me in enhancing my passion. I became a volunteer for HRRV and a new door opened for me. I learned about a new attitude, a new philosophy of death and the dying process. This new attitude focused on palliative care, providing comfort measures, education, and support to not only the patient, but to the whole family; it was a holistic approach to meeting the needs of the terminal family. Presently, I am on the Fargo HRRV Advisory Board and I am also developing five workshops for HRRV presenting material related to end of life issues.

As a graduate student, I was able to complete two field experiences directly related to death and dying. One was in a children's hospital where I interacted mostly with children who had cancer, their parents, and siblings. The other was in a long term care facility facilitating the life review process with 10 residents. Both experiences
complemented my studies as well as my personal experiences with loss. The experiences also made me want more knowledge, a deeper understanding of death and dying, and more experiences with those who are dying. My thesis was a community wide, quantitative study of attitudes toward organ donation. My passion continued.

When Dr. Klenow went on a sabbatical at NDSU, I was invited to teach his course on aging (I also have a gerontology minor) and his death and dying course. My remembrance is both excited and scared as I was to embark on this adventure. In one semester, I was hooked and developed a course proposal for a similar course on death and dying to be taught across the river at Moorhead State University (MSU). When the course offering appeared in the schedule, my excitement heightened, and when students actually enrolled in the course, I was scared to death. I will never forget the first night of "my" class. As students entered the classroom, chairs filled, the moment came for me to speak, and I spoke for three hours straight without taking a breath. I left the classroom that first night knowing the next week that only half of the students would return. That was six years ago; soon, Understanding Loss will be presented at MSU’s Academic Policy Advisory Committee (APAC) for acceptance as a permanent course offering.

Dr. Klenow telephoned me in January 1998, asking if I would be interested in assisting him with a project for HRRV; I seized the moment and accepted the invitation. The project was to be a qualitative, descriptive study of the referral process as it is experienced by those seeking hospice care in the Fargo-Moorhead area. We began the project with an informal meeting with Susan Fuglie, Executive Director of HRRV, and other hospice representatives. Goals and objectives were discussed for the study, a review of the literature was set in motion, a questionnaire was developed, consent forms put in place, and a method to recruit participants secured. The study began.

A goal was to have each participant share his/her referral story in his/her own way, perhaps with a fragile voice--some choking up in conversation, many crying during the
verbal exchange. I have contacted the perceived decision maker right after 24 hour crisis care was put in place, during the dying process, right after the family member died, and also as the hearse arrived to remove the body from the home. Not one of the participants disengaged from the interview. All of them have wanted to share their experience, their story with me.

This experience has enriched my life and deepened my understanding of life and death. I cannot help but interject the new HRRV bulletin board's message:

We enter the world surrounded by love, comfort and care . . .

Don't we deserve the same when we leave?

This is a powerful message. I have a heightened respect for HRRV and all those involved in the mission of the organization. Hospice not only provides love, comfort, and care, but it also provides unconditional support, and when possible, in the warmth of one's home surrounded by family and friends. Hospice is educational, offering clarification. Hospice also meets the pragmatic needs and challenges families encounter during this time. They supply the patient with medical equipment as well as assisting the patient and their families with the monitoring of medications. The hospice representative, be it the volunteer, social worker, or 24 hour crisis care nurse, represents support, a hand to hold, and empathy. Hospice recognizes that the dying patient is first a person. Hospice speaks to the end of life issues, to death with dignity, and to issues surrounding the quality of the terminal person's life as well as their family's. According to Bluebond-Langer (1988), dying families are, by definition, not ordinary families. Hospice intends to be respectful of this type of family.

The second rationale for this study comes from an agency concern, a concern HRRV has, which interacts with a lack of perceived community awareness of the hospice referral process, blending with my personal interest in the study. There is also a third rationale which relates to the lack of research in this area. I suspect that this study will
make a contribution to the literature as it relates to the hospice referral process and the lack of awareness the public has with regard to the totality of the process. A fourth rationale is of an educational nature. As an educator, I consider myself to be continually concerned with "how" education is "shared." It is my hope that because of this study a deeper understanding of the hospice referral process will emerge, an understanding that will assist in the development of educational tools that will promote community awareness of the hospice referral process as well as the benefits of hospice care.

A review of the literature addresses much on the content of hospice, the development of the concept, the benefits, and also the reimbursement schedule. There appears, however, to be a scant body of literature focusing on the hospice referral process.

I invite you now to embark on my personal journey. I am fortunate to have had the opportunity to participate in the data collection process for this study and even more blessed to have had the participants share their referral story with me. My life is forever changed because of this experience.

Purpose of the Study

Average length of stay (ALOS) data for hospice care tend to indicate a declining pattern for Hospice of the Red River Valley (HRRV). The National Hospice Organization (NHO) also reports a national decreasing trend in ALOS. As persons enter hospice care with fewer days of life left, hospice is finding that they need a higher level of care. Patients admit with increased medications for comfort, making it difficult for hospice to recover the high front end expenses. Locally, this has occurred in spite of the well documented fact that hospice care is more cost effective than other care modalities (Kastenbaum, 1998). In addition, reports tend to show that patient and family satisfaction with hospice care has been and continues to be quite high (Gochman & Bonham, 1988, 1990; Kastenbaum, 1998). M. L. Dahms (personal communication, May 6, 1998) reports that a survey they conducted also showed high levels of patient and family support for the areas they serve.
The decrease in ALOS has impacted hospice providers in several ways. One impact of the decreased ALOS, nationally as well as locally, is that patients are coming into hospice programs with fewer days of life remaining. It appears that hospice care is primarily end stage, death bed care with many of the benefits of hospice care consequently not being experienced by the patient and their family.

Hospice administrators and care providers at HRRV initiated a research effort to determine why ALOS is decreasing locally. In addition, HRRV is interested in understanding the process by which patients and their families are referred to hospice as well as answering the question "Why now?" as opposed to earlier or later in the trajectory of the patient's terminal illness. Hospice is available for patients and their families within the last six months of the trajectory of their terminal illness. It is also important to note that a person may be on hospice care for a period of time and, for whatever reason, find that hospice care is no longer required and go off hospice care—only to readmit at a later date. However, patients and their families tend to be admitted to hospice within the last few weeks or days of the terminal illness. Understanding the patients' and their families' perception of the referral process and "Why now?" could assist HRRV in the development and implementation of marketing and promotional strategies regarding hospice and the philosophy of care, concern, and connection to the dying patients and their families.

Data show that 30% of the HRRV eligible patients die within seven days of initial inquiry (M. L. Dahms, personal communication, May 6, 1998). Approximately 20% of those who are referred to HRRV do not admit to HRRV. Some of the patients die before being admitted and some simply prefer not to be admitted. This study conducted for HRRV showed that approximately 19% of the participant's terminal family member did not admit to hospice care; 4% reported they were either considering hospice care or were unsure; and 6% died before the decision could be made. However, approximately 71% of
the participants did admit to hospice care during the time frame of the study (M. L. Dahms, personal communication, May 6, 1998).

It is important to clarify what is meant by "referral" when objectifying the decision maker's (person signing the consent to participate form) perception of the process. For the purposes of this study, referral process, from an operational aspect, was defined as "information sharing." Anyone can make a referral call or request information related to hospice care directly from hospice. A doctor is required to document the patient's life expectancy (six months or less) and the patient's appropriateness for hospice care to certify admission. The doctor is the identified "gate keeper." Decision makers or family members do not have to wait for a health care professional to suggest hospice care to the patient or his/her family. The hospice process can be self/other initiated. Hospice may receive verbal approval from a physician certifying admission. However, HRRV must receive written documentation from a physician certifying admission with a physician's signature within 24 to 48 hours from the time of admission. Currently, the documentation can be faxed to HRRV.

Delimitations

The following were considered to be delimitations and should be considered as such when interpreting the results of this study.

1. The population was limited to participants whose family member was referred to HRRV and was served by the hospice office in Fargo only.

2. Generalizations can only cautiously be made to hospice patients from similar agency and geographic characteristics.

3. The data are "second order," that is, reported by the perceived decision maker who was often not the patient.

4. Although the instrument was subjected to several revisions, the questionnaire was not pre-tested for reliability and validity.
5. Hospice representatives were responsible for the sample. It is expected that participants were not all informed of the study, meaning that the sample would include biases based on the hospice representatives "forgetting" to invite the perceived decision maker to participate in the study.

Organization of the Study

The organization of the remainder of this study is as follows. Relevant literature is reviewed in Chapter II. In Chapter III there are descriptions of how participants were recruited for the study, how the instrument was developed, and how the data were collected. The findings of the study are reported in Chapter IV, while the summary, conclusions, and recommendations are found in Chapter V.
CHAPTER II
LITERATURE REVIEW

Chapter II will provide an overview of the literature as it relates to this study. A brief presentation of the mission and vision statements of HRRV will provide an introduction to the section. Relevant literature as it relates to the historical development of hospice care, studies focusing on hospice care, the referral process, Medicare provisions to hospice care, and a similar study conducted in 1988 will be reviewed.

The mission statement and vision statement for Hospice of the Red River Valley have recently been revised. The mission statement says:

Hospice of the Red River Valley is an independent, not-for-profit hospice serving the needs of the terminally ill and their families, in the greater Red River Valley areas of North Dakota and Minnesota. Hospice of the Red River Valley strives to improve the lives of all these people through the holistic and individualized provision of medical, psycho social, spiritual, and bereavement services of the highest quality with the utmost integrity. We provide end-of-life care to all appropriate people in our designated service area who desire our services. (M. L. Dahms, personal communication, May 6, 1998)

The vision statement is as follows:

Hospice of the Red River Valley will be the leader in palliative, end-of-life care in the upper Midwest. We will make premier hospice care available to all appropriate patients in our service area through intentional integration of hospice services into traditional health care systems through improved accessibility to hospice services with less traditional providers, and through public education of all providers and the
community at large. To realize our vision, we will foster innovation in both program development and geographic growth to ensure hospice care for unserved populations, and to meet the changing needs of patients and families. We envision a highly motivated, empowered staff whose efforts make excellence possible.

(M. L. Dahms, personal communication, May 6, 1998)

Development of Hospice Care

Hospice care is an alternate approach to caring for the terminally ill person and their family. Hospice care focuses on palliative care, not on curing the patient. Hospice care dates back to ancient times when Greek priests and other healers recognized that in health and illness, one must consider the whole person and not just the person's physical condition. Temples of healing were designed to please and soothe the ill person. Music was often a medicine involved in the healing process as well (Kastenbaum, 1998). These temples offered a holistic approach to healing analogous to the modern hospice approach to care.

During the 4th century A.D., public infirmaries (nosocomeia) were established in Greek-speaking areas of Christianity. The facilities provided care for those who would recover from epidemics as well as those who would die from epidemics. Near the end of the 4th century under the influence of a wealthy Roman widow, Fabiola, the hospice movement spread to western Europe. Fabiola not only supported the hospice concept, but she also brought the concept to Italy where she supported it financially and also served as a nurse. Hospice appears to have been well established by the 5th century (Kastenbaum, 1998).

The term "hospice" derives from hospitium, a Latin term related to host and hostess. The medieval hospice was usually a house offering food, shelter, and comfort under Christian auspices for those in need. During the Protestant Reformation, the religiously-oriented hospice, with its mission of mercy to the dying, faded away and were
replaced with state run institutions with a different philosophy. Bureaucracy and
technology oriented medicine tended to be the norm. Today, the term hospice, according to
the National Hospice Organization (1998a), refers to "a steadily growing concept of
humane and compassionate care which can be implemented in a variety of settings—in
patients' homes, hospitals, nursing homes or freestanding inpatient facilities" (p. 1).

In 1879, the renewed hospice approach made its appearance with the opening of
Our Lady's Hospice in Dublin, Ireland (Gilmore, 1989). Sister Mary Aitkinhead led the
way, and in 1905, another hospice facility, St. Joseph's Hospice, opened in London,
England. A medical officer at St. Joseph's Hospice introduced improvements in pain
control for the dying patients. The hospice movement took one step forward in the
development toward its current philosophy of care.

St. Christopher's Hospice, located in a residential suburb of London, England, was
founded by Dr. Cicely Saunders in 1967. St. Christopher's has become a model, as well
as an inspiration, for the development of several other hospices. Dr. Saunders is
responsible for the development and implementation of the modern day hospice philosophy
of care. The current hospice philosophy of care reflects a

special kind of care designed to provide sensitivity and support for people in the
final phase of a terminal illness. Hospice care seeks to enable patients to carry on
an alert, pain-free life and to manage other symptoms so that their last days may be
spent with dignity and quality at home or in a home-like setting. (National Hospice
Organization, 1998a, p. 1)

Dame Cicely Saunders credits two individuals with inspiring her and assisting her
in the introduction of modern hospice care. One was a Salvation Army matron, Lillian
Pipkin, who taught her the basics of pain management for the terminally ill. The other was
a dying man by the name of David Tasma (Kastenbaum, 1998).
In 1974, one hospice existed in the United States, the New Haven, Connecticut, Hospice. The Connecticut Hospice, Inc. was the first and remains the only accredited teaching hospice. This hospice provides teaching and consultation to professionals around the world under the auspices of the John D. Thompson Hospice Institute for Education, Training, and Research, Inc. The mission statement of The Connecticut Hospice, Inc. emulates all hospice mission statements:

The Connecticut Hospice, Inc. provides quality and compassionate care to patients suffering from irreversible illness and to members of their families. Care is interdisciplinary in nature and allows for family decision-making and participation. The goal is to enhance the quality of life for as long as life lasts. Care given in the home, Inpatient center and Hospice Cottage serves as a clinical model for our education, training and research efforts made essential by our unique role as the founder of hospice care in America.

Hospice is more about a philosophy than a medical facility. Our goal is maximizing life and enjoyment. At Hospice we have respect for the individual, and the individual is a person as much as a patient. Hospice is about people taking care of people, business aside, the way caring should be. All ages, all diseases, all regardless of ability to pay. (The Connecticut Hospice, 1998, p. 1)

Two thousand hospice organizations now exist across the United States (Kastenbaum, 1998). The standards outlined by the 1975 International Task Force guide the hospice movement. Hospice organizations define themselves as follows:

Hospice is a special kind of care designed to provide sensitivity and support to the terminally ill patient and family. The hospice philosophy encompasses the concept that death is a normal phase of life. We help patients remain pain-free and alert so that their last days may be spent with dignity and quality at home or in an inpatient setting. Services are provided by a team of trained professionals and volunteers
who provide medical care and supportive services not only to the patient, but to the entire family. (Community Hospice, 1992, p. 1)

In 1975, an International Work Group on Death and Dying, including Saunders and others, began to develop guidelines for hospice care. A list of the "Hidden or Implicit Standards of Care" was developed (Kastenbaum, 1998, p. 123). The International Task Force also recommended these proposed standards: "Patients, family, and staff all have legitimate needs and interests. The terminally ill person's own preferences and lifestyle must be taken into account in all decision making" (p. 123). The specific standards focused on three areas: "Patient-Oriented Standards, Family-Oriented Standards, and Staff-Oriented Standards" (pp. 123-124).

In 1994, the National Hospice Organization (NHO) elaborated further the philosophy of hospice care. They compared hospice care with traditional care. The following provides an overview of the comparisons as listed in Death, Society and the Human Experience (Kastenbaum, 1998):

- Hospice treats the person, not the disease.
- Hospice emphasizes quality, rather than length of life.
- Hospice considers the entire family, not just the patient, as the "unit of care."
- Hospice offers help and support to the patient and family on a 24-hour-a-day, seven-day-a-week basis. (p. 125)

Medicare Provisions to Hospice Care

Hospice was accepted by the federal government as an integral component of the health care system in 1983. The above statements are consistent with the regulations established by the Health Care Financing Administration. The National Hospice Reimbursement Act of 1983 established a Medicare hospice benefit. The benefit provides
full service for Medicare appropriate hospice care. The Medicare hospice benefit applies only when the following three conditions are satisfied (Miller & Mike, 1995):

1. The patient's physician and the hospice medical director certify that a patient has a life expectancy of six months or less.

2. The patient chooses to receive care from a hospice as an alternative to basic Medicare coverage.

3. Care is provided by a hospice program certified by Medicare. (p. 537)

Hospice care is available as a benefit under Medicare Hospital Insurance (Part A). Should a patient opt for hospice care under the Medicare benefit, they will receive non-curative medical care and supportive services for their terminal illness. To be eligible for Medicare reimbursement, the hospice must be a Medicare approved program and a physician would need to certify that the patient has a life expectancy of six months or less if the disease runs its expected course. Many patients are unaware of the following provision to the Medicare benefit:

Special benefit periods apply to hospice care. A Medicare beneficiary may elect to receive hospice care for two 90-day periods, followed by an unlimited number of 60-day periods. The benefit periods may be used consecutively or at intervals. Regardless of whether they are used one right after the other or at different times, the patient must be certified as terminally ill at the beginning of each period.

A patient who chooses hospice care may change hospice programs once each benefit period. A patient also has the right to cancel hospice care at any time and return to standard Medicare coverage, then later re-elect the hospice benefit in the next benefit period. If a patient cancels during one of the first three benefit periods, any days left in the period are lost. (National Hospice Organization, 1998c, p. 2)
In return for financial support, a hospice must agree to the following (Kastenbaum, 1998):

- Ensure continuity of care and professional management at all times, whether the patient is at home, in a hospital, or a respite care setting.
- Establish and maintain a detailed plan of care for each patient.
- Evaluate quality of care and correct any problems that are identified.
- Provide an interdisciplinary team that includes a physician, registered nurse, social worker, and a pastor or counselor.
- Comply with licensing regulations in its state and locality.
- Maintain clinical records for each individual receiving hospice care.
- Provide all the core services required by the individual, and any additional services that might be needed (physical therapy, speech-language rehabilitation, etc).
- Guarantee that essential services are available around the clock, every day.
- Operate an in-service training program to maintain and improve the skills of staff and volunteers. (p. 126)

Barriers to hospice care tend to be the patient not being eligible for Medicare Hospital, Part A benefits, or if the patient does not have a strong trusting relationship with a primary physician. Other obstacles include a physician's difficulty with the hospice admission criteria, reluctance to lose control of the patient and, sometimes, restrictions on the number of pain medications they are allowed to prescribe. Other barriers include lack of family cooperation with hospice; poor communication between terminally ill patients, their families, and health care professionals; and late referrals to hospice care (Kastenbaum, 1998).

As of summer 1998, 80% of hospices were Medicare certified. It is reported by the National Hospice Organization (1998b) that in 1994 Medicare spent $1.2 billion of its $200
billion budget on hospice care. At the time of this study, 42 states covered hospice care under Medicaid (including the District of Columbia) and in 1993, $129 million was spent on hospice care that was Medicaid reimbursable. In 1997, the Medicare per diem rate for hospice care was approximately $94.17 per day for home care and for general inpatient care the cost was estimated to be $418.93 per day. Hospice care is also covered under most private insurance plans and 82% of managed care plans do offer hospice services as of summer 1998 (National Hospice Organization, 1998b). Should a Medicare beneficiary choose hospice care, Medicare will not pay for care from another provider which would duplicate any care provided by hospice, care that is provided by a health care provider not arranged by hospice, nor will Medicare pay for treatment of the terminal illness which is not for symptom management and pain control (National Hospice Organization, 1998c).

Hospice Literature Related to This Study

The National Hospice Organization (1998b) reported in June 1997 that there were approximately 3,000 planned or operating hospice programs in all 50 states as well as in the District of Columbia and Puerto Rico. Hospice growth has increased by 17% in the past five years. In 1997, it is estimated that hospice served 450,000 patients in the United States alone.

In 1995, 60% of all those who died of cancer in the United States were under hospice care. In that same year, 6% had a heart-related diagnosis, 4% of AIDS patients who died in the United States in 1995 were also receiving hospice care, 1% had renal diagnoses, 2% Alzheimer's, and 20% of those under hospice care reported "other" as the terminal diagnosis (National Hospice Organization, 1998b). Also, the National Hospice Organization (1998b) reported that, in 1995, "60 percent of hospices admit patients without primary caregivers; another 27 percent admit patients without [primary] caregivers on a case-by-case basis" (p. 2). To date, this does not appear to be the case at HRRV as patients are not admitted to HRRV without a designated care giver. In addition, in 1995,
the National Hospice Organization (1998b) reported that "53 percent of hospice programs admit individuals requiring 'high-tech' therapies; an additional 39 percent admit patients needing 'high-tech' services on a case-by-case basis" (p. 2). Physicians making referrals to the HRRV report that they vary in this area. Many of the physicians making referrals to HRRV view treatment options as not being palliative and tend to not certify admission if a patient is still seeking a treatment modality, which seems to be consistent with Medicare.

Approximately 32% of hospice programs in the United States had budgets in excess of $1 million in 1995, 18.7% reported having budgets between $500,001.00 and $1 million, and 50.1% reported having operational budgets of less than $500,000.00. In 1992, 72% of American hospice programs were either Medicare certified or reported certification as pending (Licht-Lattanzi & Connor, 1995) compared with the 1998 report that states that 80% of hospices are currently Medicare certified (National Hospice Organization, 1998b).

The majority of hospice programs in the United States are not-for-profit (65%), with 16% of the hospice programs nationally reporting being for profit. Four percent of the hospice programs in the United States are government operated and 15% are "other" (National Hospice Organization, 1998b). Twenty-one percent are a division of a home health agency, 37% are a division of a hospital, and 40% report being independent hospice facilities.

Nationally in 1995, 52% of hospice patients were male, 71% of them being 65 years of age or older, and of the females (48%), 74% reported being 65 years of age or older. Ethnically, 83% of the national statistics for admission to hospice care were Caucasian patients, 8% of the admits reported being African American patients, 3% of the admissions were Hispanic patients, 1% of the reported admissions were Native American patients, and 2% of the admissions reported self as being "Other Race." Seventy-seven percent of hospice patients were reported to have died at home in 1995 (National Hospice
Organization, 1998b). In 1992, statistics show that 55% of hospice patients reported living with a spouse, 20% of hospice patients reported living with their children, 10% reported living with a significant other, and 5% reported living with parents (National Hospice Organization, 1993). Also, in 1995, 19% of hospice patients died in an institutional setting and 4% in "other" settings. On average, 22% of patients in a hospice program nationally reported having a terminal illness other than cancer in 1992 compared with 60% in 1995.

According to an article by Christakis and Escarce (1996), 1 patient in 6 die within seven days of admission to a hospice program and 3 patients in 10 die within 14 days of admission. In addition, the median length of survival for hospice patients was reported to be 36 days after admission. In 1995, the ALOS nationally for all patients admitted to a hospice program was 61.5 days (National Hospice Organization, 1998b).

Information reported by HRRV (M. L. Dahms, personal communication, May 6, 1998) showed that 98% of their admits to be Medicare reimbursable, 2% to 3% are under 65 years of age, and 30% were on home health care prior to admission to hospice care. HRRV reported that 60% of their patients have cancer as the identified illness, 40% report "other." On average, 31% of the admitted patients ALOS is 1 to 8 days, 36% of the admitted patients ALOS is 8 to 31 days, and 35% of the patients reported an ALOS of 32 days or more. Study participants reported that 63% lived at home, 36% reported living in LTC facilities, and 1% reported as being "in transition." Fifty-five percent reported cancer as their terminal illness, 12% reported chronic obstructive pulmonary disease as the terminal illness, 11% reported chronic heart failure as the terminal illness, 8% reported failure to thrive as the terminal illness, and 3% reported Parkinson's disease as being the terminal illness. Chromosome abnormality, cirrhosis of the liver, end stage dementia, end stage heart disease, gangrene, kidney infection, myelodysplastic, paralyzed bowel, primary lateral sclerosis, stroke, and trisome 18 were each respectfully reported as the terminal illness in 1% of the cases.
In 1996, a nationwide Gallup survey conducted for the National Hospice Organization revealed the following participant thoughts with regard to hospice care:

- Nine out of ten adults would prefer to be cared for at home if terminally ill with six months or less to live. The majority of adults would be interested in a comprehensive program of care, such as hospice.
- Belief on whether or not it should be legal for a physician to participate in assisted suicide was split; however, men are more likely than women to feel it should be legal.
- Only 35% of adults surveyed reported, if terminally ill, they would ask their doctor to help end their life.
- When asked to name their greatest fear associated with death, respondents most cited "being a burden to family and friends," "pain" was the second most common fear.
- Most adults (62%) believe it would take a year or more to adjust to the death of a loved one, yet few (10%) of the general public have ever participated in a bereavement program of grief counseling following the death of a loved one.
- Nearly 90% of adults believe it is the family's responsibility to care for the dying. (National Hospice Organization, 1998b, p. 3)

Literature Reviewed Relevant to the Study

Du Bois (1980) described the role of hospice as being a supplement to traditional medical services, not a substitute. An aim of hospice care is to assist the terminally ill patient to avoid hospitalization, and when possible to die at home. However, at times patients do require medical intervention and institutional care may also become necessary. Bass, Pestello, and Garland (1984) described hospice care as an "alternative approach for the care of the terminally ill" (p. 199). The study by Bass and colleagues focused on patients enrolled in a hospice program and place of death. One hundred forty-six terminal
patients, all admitted to an in-home hospice program, which was part of a not-for-profit home health care agency, participated in the study. Approximately 43% of the patients died in the facility and 57% died at home. Factors discussed as they related to place of death included (a) number of visits from hospice nurses, (b) the intensity of the contact with hospice nurses, (c) length of time patients were enrolled in the hospice program, and (d) race of the patient. The study's hypothesis suggested that the more social support the patients and his/her family receive during the "stressful situation" (p. 201) the more likely those involved will cope in a successful manner with the stressful situation. If a patient died at home, which was identified as the "stressful situation" (p. 201), then the hospice program was perceived as being successful.

This study found that patients with shorter stays in the hospice program tended to die at home. In addition, the more registered nurse visits a patient received, the more likely the patient was to die at home; white patients tended to die at home more often than non-white patients, and non-white patients tended to die in a health care setting.

The study by Bass et al. (1984) appears to suggest that the number of days a patient was enrolled in a hospice program to be a predictor of where the patient will die. It appears that patients enrolled in the HRRV program die shortly after admission in their identified place of residency, which is similar to this study's findings.

Bass and Labus (1985) found that patients with longer stays in a hospice program tended to indicate an earlier admission date to hospice care. Social factors along with receiving a terminal diagnosis (patient expected to die within six months if the disease runs its expected course), extraneous measures not being accessed to prolong the patient's life, a shift from curative modality to a support and palliative modality, and physician training all tend to influence the time at which a patient is admitted to hospice care. The decision appears to be based on objective factors (physical condition) as well as subjective dimensions. Admission to a hospice program, according to Bass and Labus, also tends to
be impacted by the patient being Medicare appropriate. Again, they stated that for a patient to be appropriate for Medicare hospice reimbursement, the patient would need to have a home-based primary care giver, or would need to have the ability to hire an aide to act as their primary care giver assuming all care giving obligations.

In reality, the patient in most need of hospice care may actually be a patient without a primary home-based care giver, who also may lack the social support systems available to be designated as a primary home-based care giver, and who also may lack the financial resources to hire care. Section 122 of the Tax Equity and Fiscal Responsibility Act of 1982 made hospice a reimbursable service. It also added a structural constraint to the timing involved in a patient's opportunity to access hospice services (Bass & Labus, 1985). For example, hospice care will be reimbursed for a maximum of 210 continuous days. In essence, the dilemma: the patient who lives too long becomes an economic liability, and the patient who dies too quickly (receiving 24 hour crisis care) is also a liability. Twenty-four hour crisis care tends to be the most expensive level of care for hospice programs. These patients, those on 24 hour crisis care, also tend to experience the least amount of supportive, social, and psychological benefits from the hospice program. Based on Medicare criteria for eligibility to access hospice care, patients may not be referred to hospice by a health care professional if the health care professional does not understand the eligibility criteria for admission and perceives the patient as not being within the 210 day reimbursement period. And hospice programs may not admit the patient to full hospice care if the patient is not perceived as appropriate for Medicare reimbursement.

Most patients are currently admitted to hospice programs with few days of life remaining. It appears that patients who would be appropriate for hospice care based on the physiological dimension of his/her disease may in fact not be admitted due to social factors, such as not knowing they are terminal, not being willing to cease aggressive treatment
modalities, not having a primary care giver available to care for them, not having insurance with a hospice benefit, and not being eligible for Medicare reimbursement.

Bass and Labus (1985) perceived this social aspect as being a subjective dimension that has created barriers for admission to hospice programs. Patients with family members, significant others, or the ability to hire primary care givers tend to admit to hospice later in their illness. The patient also tends to utilize his/her personal support systems as long as possible and to admit to hospice programs only when primary care givers become exhausted and personal support systems become depleted. In addition, Bass and Labus report that the more individuals who are available to assist with the patient's care, the later in the illness the patient will seek information related to hospice care.

Bass and Labus (1985) conducted a study of 726 patients using seven hospice programs between January 1, 1982, and December 31, 1982. Results of the study suggest that the degree of physical deterioration to have the greatest impact on length of stay as did having an available care giver and not the number of available care givers. It is interesting to note that physicians who specialized in either family practice or osteopathic medicine to have referred terminally ill patients more often to hospice programs than did oncologists. They also found that physician referral to hospice care to occur only after curative treatment options had been exhausted.

In summary, Bass and Labus (1985) concluded that admission to hospice programs occurs following a range of treatment options; having a care giver available delayed onset of hospice services, and it appears that an oncologist's familiarity with cancer and the treatment options may in fact delay the patient's referral to hospice care when compared to osteopaths or family practitioners.

According to Calnan (1983), the decision as to when to seek medical help is a social process and tends to involve one person other than the patient. He also states that recent research (pre-1983) suggests that the patient would consult with friends rather than family.
This contradicts the findings of this study for HRRV; it appears that patients in this study tended to consult with care givers as well as decision makers when seeking hospice care, both of whom tended to be family members and not friends.

There appears to be confusion surrounding the concept of social support and the types of support related to the different types of stressful situations. According to the "needs model" of stress, individuals have needs that are satisfied through social interaction with other persons and needs that are unmet tend to create stress. The "transactual model" of stress perceives stress as occurring when "perceived demands exceed perceived resources" (Jacobson, 1986, p. 251). The "transition model" of stress perceives stress as resulting from change which includes both losses and gains or psycho-social transitions. The "transition model" of stress will be discussed as it is perceived to relate to the hospice decision making process from my point of understanding of the models presented by Jacobson. The decision maker has recently been confronted with the option of admitting his/her family member to hospice care, or just considering admission to hospice care. The event that triggered this discussion tends to create a psycho-social transition for the patient and the decision maker as well as the care giver. The change impacts all individuals involved psycho-socially as well as impacting them in their holding environment.

The decision maker's assumption with regard to the trajectory of the patient's terminal illness can shape his/her behavior pattern as well as the meaning he/she attaches to the hospice concept. Interpretation appears to be significant during the decision making process. For example, if the decision maker perceives the patient as being near the end, death occurring in the imminent future, they tend to admit to a hospice program. He/she defines the experience as stressful and accesses hospice care for crisis care, for end stage, death bed care.
The "transactual model" focuses on the individual's "beliefs" (Jacobson, 1986, p. 251) and the significance attached to the event by those involved. If the decision maker believes the patient has a short time left to live (days) they perceive the event (illness) to be stressful and tend to admit to hospice care faster. Transitionalists also consider "how things are in the environment" (p. 251). If the decision maker perceives of the environment as being in need of accommodations to assist he/she in caring for the medical, physical, psycho-social needs of the patient, then he/she will also perceive of hospice care as being instrumental in meeting those needs and tend to admit to hospice sooner. For example, if a hospital bed or oxygen are presently needs that are not being met due to financial constraints, but could be met by admitting to hospice, the admission will occur.

The timing of support appears to be dependent not only on the referral process to hospice, but also on the decision maker's perception of the stressfulness of the illness. If the decision maker believed the need for guidance, support, expertise, professional care, equipment, etc., exists, then the need is satisfied through admission to hospice care for the patient. According to Jacobson (1986), beliefs refer to the significance, implications, or meanings an individual attaches to an event or demand, and how the meaning affects the individual's well-being. For this study, it appears that admission to hospice care was not only dependent on the referral process as well as patient needs, but also on the decision maker's perception of the event, the care giver's perception of the event, and the demands placed/assigned to them.

Part of the referral process is dependent on the staging of negotiations between the hospice program and health care professionals. According to Levy (1982), "Staging refers to the use of self-serving strategies by individuals and interest groups to define and control the context in which negotiations occur" (p. 283). An article by McCarthy and Zald (1973) reports that as a modern social movement, the survival and growth of hospice is in part dependent on convincing other individuals and organizations that there is a need for hospice
care. It appears that the negotiations that occur between hospice representatives and institutional gate keepers, who tend to be in control of health care resources, need to be positively defined for individuals and institutions to provide resources such as public support, legal entitlements, money, and for health care professionals to refer patients to hospice care.

For staging negotiations to be successful in the referral process, Levy (1982) stated that trust, as a necessary element, must be established. Oftentimes health care professionals will encourage patients to participate in clinical trials or to continue with extraneous measures, aggressive treatment modalities, which will prolong the referral to hospice care. The hospice model of palliative care tends to contradict the medical model of care. Gochman and Bonham (1988) conducted two complimentary studies examining the different dimensions of physician involvement in a patient's decision to enter hospice care. The first study was a mail survey of physicians in three communities served by Medicare certified hospice programs. Questionnaires were mailed to 849 physicians in Kentucky. The sampling frame for this study was a June 1985 list of licensed physicians practicing in three communities provided by the Kentucky Medical Association. The response rate for the study was 45%. Of those who responded, 90% had heard of hospice and 90% of the comments about hospice were favorable.

In the study by Gochman and Bonham (1988), awareness of hospice services appeared to be related to the type of community in which the physician practiced. In addition, his/her type of practice, the number of terminally ill patients they see, as well as the physician's perceived responsibility for disclosing to the patient the terminal aspect of his/her illness, were other factors considered in degree of awareness of hospice services. Physicians in smaller, less urban communities reported having a greater degree of awareness of hospice services than physicians in the larger, more urban communities.
Physicians with primary care practices reported an increased level of awareness of hospice services when compared to physicians who specialize, unless the physician who specialized had the primary responsibility for the patient's care. In that case, there was no reported difference in level of awareness. In addition, in Study I, Gochman and Bonham (1988) reported that physicians who treat larger numbers of terminally ill patients and who had the responsibility for disclosing the terminal prognosis of the patients' illness to them were also more likely to be aware of hospice services.

Study II conducted by Gochman and Bonham (1990) focused on two objectives. The first was why the physicians "recommended or endorsed hospice care" (p. 43), and the second was "the degree to which physicians were satisfied with the decision for the patient to enter hospice care" (p. 43). Face-to-face intensive interviews for 150 cases were conducted in the same communities identified in Study I during the last four months of 1985. Those interviewed included the patient, care givers, other decision makers, and attending physicians. The results of the study indicated support provided to the patients and care givers as being the most important factor in considering hospice care for the physicians. Eighty percent of those interviewed reported being "very satisfied" with hospice care, 17% reported as being "satisfied" with hospice care, and 3% reported as being "dis-satisfied" with hospice care (p. 45). Fifty-five percent of those interviewed reported dying at home as being an important aspect associated with hospice care, and 66% reported pain management as being an important aspect of hospice care.

In summary, according to the study by Gochman and Bonham (1988), physicians in smaller communities, where they have direct responsibility for the patient's care and disclosure of the patient's terminal prognosis, tend to be more involved in discussing hospice care as an option with the patient and his/her family. Also, physicians surveyed for this study reported as being aware of the hospice concept and philosophy of care and also as being satisfied with hospice services.
The first study conducted by Gochman and Bonham (1988) has been reviewed. This study, referred to as Study I, focused on the discussion and decision making process to enter hospice care. In Study I, physicians, patients, care givers, and other decision makers of 150 hospice cases were interviewed. They also conducted a complementary study, Study II, which was a mail survey. The questionnaires were mailed to the survivors of those whose family member died of cancer. Both studies reported respondents as having a high level of awareness with regard to hospice care. Study I showed that the initial discussion related to seeking hospice care to be initiated by friends, relatives, and then physicians. The final decision maker was identified as the care giver in 66.38% of the cases when asked, "Who made the final decision for [patient] to enter hospice?" (p. 24). However, almost half of the patients reported as perceiving his/herself as being responsible for making the final decision to seek hospice care. When compared to the findings of the HRRV study, daughters were identified as the perceived decision maker in 31% of the cases; 22% of the perceived decision makers were identified as being the wife of the patient; a son was identified as the perceived decision maker in 15% of the cases; the patient him/herself was identified as the perceived decision maker in 10% of the cases; and in 10% of the cases, the husband of the patient was identified as the perceived decision maker.

Study II, a mail survey, included questionnaires being sent to 1,038 cases of families in Kentucky who had lost a family member to cancer, whether or not hospice had been used. The sampling frame, death certificates, was obtained from the Cabinet of Human Resources in Kentucky. Questionnaires were returned for 446 of the cases, or a response rate of 42.97%. In 99.55% (all but 2), of the cases, the respondent was a spouse, child, sibling, or identified as another family member (Gochman & Bonham, 1990).

The results of Study II show that 62.58% of the respondents had heard of hospice prior to their loved one becoming ill. Physicians were most frequently reported as being
the source of information, and 40.98% of the respondents reported receiving information about hospice during the illness. Results of the HRRV study suggest that 96% of the respondents had heard of hospice care prior to his/her loved one becoming ill; 36% reported receiving information at that time; and of the 36% who did receive information, the most frequent reported source of the information sharing was reported to have been the hospice brochure (34.9%), with hospice representatives reported as being the second most reported source of information sharing during the initial referral informational meeting (32.6%) (Gochman & Bonham, 1990).

In comparing the results of the Gochman and Bonham studies, Study I with Study II, it appears that in Study I the initial information about hospice care is communicated to the patient by friends and relatives. Study II complements the findings of Study I; however, once the terminal prognosis of the illness is known, the physician is then identified as the "single most frequent source of hospice information" (Gochman & Bonham, 1988, p. 29). Interestingly, Study II reported that the actual timing of communications with regard to hospice care to have the greatest impact on the decision to admit to hospice care. Families who had heard of hospice, but who received no additional information about hospice during the illness, were seven times less likely to report even considering hospice care for the patient. It appears that information about hospice care should be communicated to families following the diagnosis of the patient’s terminal illness. Gochman and Bonham (1990) stated:

The period following diagnosis of a terminal illness is a critical time for making decisions about care, and if communication of information about hospice care, services, and availability is provided during this period, then the chances are greatly increased that hospice care will be considered. If information is not provided during this time, then the chance that hospice care will be considered are very small. (pp. 29-30)
The articles by Gochman and Bonham (1988, 1990) were reviewed prior to the development of the questionnaire for this study and served as a guide for the development of questionnaire items. The questionnaire (Appendix C) replicates some of the items in the 1990 study conducted by them in Kentucky. Specifically, HRRV was interested in understanding more about the decision making process and the referral process when seeking hospice care, who the perceived decision maker actually is, why he/she is accessing hospice care at the point in time that he/she is, perceived benefits of hospice care, as well as who initiated the discussion and when the discussion was initiated. Items replicated in the HRRV questionnaire included:

1. When was hospice care first considered?
2. Who initiated the discussion?
3. Who made the final decision to seek hospice care?
4. Was anyone involved in the discussion? If so, who?
5. How did you first become aware of hospice care?
6. Did you receive information? (Gochman & Bonham, 1990, pp. 20-21)

Bebko (1995) reported that despite the fact that hospice appears to be one of the fastest growing segments in the health care industry, those involved in the referral process tend not to be adequately informed with regard to the services hospice provides. Bebko defines hospice as "a philosophy of caring and an array of services for the terminally ill patients which is an alternative to conventional care traditionally available to them" (pp. 79-80). It appears that the rate of hospice patients has grown over the past 10 years, but one of the challenges faced by many hospices is that of stagnant referral patterns as well as uninformed care providers with regard to the range of services provided by hospice programs. For example, it was expected that Medicare hospice benefits would have reimbursed care for 40,000 patients in 1985, when in reality only 18,000 patients used the Medicare benefit to pay for hospice care.
In 1992, a survey conducted by the National Hospice Organization reported that 86% of Americans would prefer to die at home, but that of that 86% only 22% mentioned hospice as an option of care. Bebko (1995) hypothesized that gate keepers were unaware of the complete range of service options provided by hospice agencies. Gate keepers for the study conducted by Bebko were identified as physicians, social service workers, administrators, clergy, and nurses working in home health agencies. A total of 220 surveys were distributed (160 mailed, 80 hand delivered) to determine gate keeper factors as they relate to the hospice referral process. Thirty-seven percent of the surveys were returned (82 completed questionnaires). Twenty-seven nurses, 26 clergy, 15 physicians, 8 social service workers/administrators, and 6 unidentified participants responded to the survey.

Respondents were asked to rate their level of familiarity with hospice services and features using a Likert scale. They were also asked to evaluate hospice based on nine identified features. It appears that all of the gate keepers felt they were aware of the supportive services provided to families by hospice. However, gate keepers reported not being familiar with the benefit coverage for hospice provided by Medicare. Respondents (gate keepers) also tended to be unfamiliar with the range of services provided by hospice. Clergy reported being the least familiar across the spectrum; social workers and social agency administrators reported being the most familiar with all of the services provided by hospice. However, it appears that all groups had inadequate information as it related to Medicare benefits. In conclusion, stagnant referral patterns tend to be a function of the lack of knowledge of services provided by hospice agencies as well as a lack of familiarity and understanding about Medicare benefits as they relate to hospice care.

The next chapter will provide an overview of the methods employed in conducting this study.
CHAPTER III
METHODS

Description of the Method of Participant Recruitment

The methods employed for this study are discussed in this chapter. Hospice of the Red River Valley receives approximately 600 referral calls per year from their entire geographical network. This study will focus on data gathered from referrals made in the Cass/Clay County area. A census approach, non-probability sampling, was employed in which each referral call was solicited for participation in the study. The recruitment for the study took place over a nine month span in order to attract a sufficient number of referrals for analysis. One hundred referrals were included in the study.

At the referral visit, consisting of a face-to-face interview with hospice representatives (usually a hospice registered nurse and a hospice social worker), the referring party was invited to participate in a study of hospice care and the referral process. In some cases, there was not a family care giver for the patient. At times, the referral person was geographically removed from the area; when this occurred, the person was still contacted to participate in the research study. Those who agreed to participate tended to be contacted within 24 to 48 hours after the consent form was signed (Appendix A) at the initial referral visit, or as soon as possible thereafter. The hospice representative explained the purpose of the study and invited the perceived decision maker (who may or may not have been the care giver) to participate in the study. Those agreeing to participate by signing the consent form were contacted via a telephone interview. In some of the cases, the perceived decision maker requested that another family member (usually a daughter) participate in the study. On those occasions, it tended to be because the perceived decision
maker did not feel he/she could speak to all of the reasons the family was seeking hospice care at this time nor to all of the benefits they would realize from having hospice care at this time.

Research Design/Instrumentation

The telephone survey format was constructed following the suggestions in Dillman (1978), who outlined the procedure in a step-by-step format. Because the sample was a census approach, it was not necessary to establish a sampling frame from which to draw the sample. In addition, a letter was not forwarded to the participants introducing the study, because hospice representatives had presented the study at the initial referral interview. Hospice representatives verbally informed the participants of the study and requested their participation. Once the participant agreed to be contacted, the hospice representative obtained written consent from the perceived decision maker and indicated that a contact would be made shortly.

As the identified research associate for this study, I contacted HRRV daily to obtain names and telephone numbers of those signing consent forms to participate in the study. In addition, basic demographic information was obtained as well as any background information the hospice representative may have received at the time of the referral visit that would facilitate the contact. The original signed consent forms were kept in the HRRV Fargo office. Copies of the consent forms were forwarded to me immediately by a hospice representative. Consent forms were duplicated and one was attached to the completed questionnaire, while one was kept in a secure place for follow-up research.

The telephone interviews were conducted by this writer. The questionnaire used for this study was developed and is found in Appendix B. The interview format included both open-ended and close-ended questions. The format was quite flexible for the purpose of learning as much about the referral story as possible from the perceived decision maker.
The opportunity for probing presented itself on several of the contacts. Each contact ranged from 10 to 60 minutes in length.

Study Objective

The objective of the interview was to have the person who knew the most about the referral process share how the patient came to be referred to hospice, reasons for the timing of the contact, and perceived benefits. The person interviewed was identified as the perceived "decision maker" in all but three of the cases.

On contact with the perceived decision maker, I identified myself, the study's goals, and the approximate amount of time it "could" take to complete the interview process. In addition, I facilitated the questionnaire allowing the perceived decision maker ample time to share his/her referral story. The initial question in the interview set the stage for the interview format: "Please share with me how your family member came to be referred for hospice care." Once the interview began, the open ended structure prevailed. Only when necessary did I ask specific questions of the participant. However, if the questions were not answered in the perceived decision maker's referral story, the questions on the questionnaire were then asked. Active listening and effective probing were both instrumental to the success of each completed interview. The goal was to have the respondent share his/her referral story in as much detail as possible. The probing process was needed to elicit the point at which hospice was suggested, who the referring agents were, why hospice was being contacted at this point in time, and any specific benefits of hospice care that may not have been mentioned. In addition, I probed to determine if there were differences of opinion regarding appropriateness of seeking hospice care as well as the nature of any objections to such care.

For the purpose of this study, the unit of analysis was the perceived decision maker regarding hospice care. Time was relevant due to the date of admission to hospice care in respect to the length of stay. The study was a cross sectional study in a natural setting.
The study was of importance to hospice and their understanding of the perception of the referral process for the patient and the decision maker, perceived benefits for the patient and their family, as well as answering the question "Why now?"

Research Design Discussion

Research designs tend to be classified according to three main purposes and the research design tends to be guided by the purpose. There are three general research purposes: Is the study to be exploratory, descriptive, or explanatory?

The purpose of the study was exploratory in nature, so a flexible design would be more appropriate than a structured design that tends to be inflexible. A design that draws conclusive and logical inferences and allows for generalizability is not necessary for an exploratory study. An exploratory study hopes to gain new insights allowing for future study of the area to be developed and implemented.

Exploration, as a research purpose, is concerned with discovering the way things are. You may want to understand a social phenomenon better or to satisfy one's curiosity; then a feasibility study uses exploration to see if a more comprehensive study is warranted. In addition, a feasibility study may assist with the development of methods to be used in a more comprehensive study, and an exploratory study can also assist with the development of a hypothesis. Exploratory studies tend to be inductive.

Descriptive studies may be used for the primary purpose of determining frequency with which something occurs or in association with something else and also to accurately portray the characteristics of the units of analysis. Descriptive research tends to concentrate on accuracy and completeness and typically tends to be more precise than studies with a predictive or causal purpose.

If the purpose of the study is to describe or to explain, it then becomes important to pay attention to certain logical principles in the design. When the design is descriptive, certain generalizations may be made with regard to the attributes of the sample of the
population being studied. Descriptive studies seek to describe the characteristics of a population accurately based on the sample used for the study. The more confident the researcher is that the sample is representative of the population, the more confident the researcher will be with regard to the generalizations made about the sample.

When a researcher is concerned with why things are the way they are, the purpose would be to explain. According to Guy, Edgely, Arafat, and Allen (1987), an explanation is the most advanced of the three scientific purposes and that to do this research with this purpose in mind, the researcher needs to have an increased knowledge of the research question. If researchers can explain, they can predict, which means a cause-effect relationship can be posited among variables. To establish beyond a probable doubt that a cause-effect relationship exists, a relationship between the two variables must exist and they must co-vary together and cause must precede effect. In other words, a time order between the two variables must exist (independent variable before dependent variable) and finally all other possible explanations (hypotheses) must be eliminated. This purpose tends to be theory dependent, deductive reasoning based, and was not appropriate for this study.

This study began with a descriptive purpose, to determine frequency and to portray the characteristics of the decision maker and his/her perception of the referral process as well as the benefits of hospice care as accurately as possible. However, as the study progressed, it became apparent that the study was also of an exploratory nature. Clearly, the study did, in fact, provide new insight and direction for future study. In addition, the study will assist HRRV in understanding the referral process, the response to their question "Why now?," as well as perceived benefits of hospice care.

There are three general research designs to consider when conducting a research project: the experiment (or quasi-experiments), the survey, and the field study. The design of choice for this study was the survey design. According to Rubin and Babbie (1993), "Research design refers to all of the decisions made about how a research study is
conducted" (p. 330). This section will discuss the survey design as it was the design of choice for this study.

**Survey Research Design**

Survey research tends to gather a considerable amount of information from a sample that can often be generalized to an entire population. Survey design can be used for any research purpose but tends to be used for descriptive purposes. It is important to note that surveys may use statistical groups that tend to be independent of the setting, and they also tend to be representative and can be cross sectional or longitudinal studies. Most surveys tend to be cross sectional survey designs that involve asking questions to collect the data by conducting either focus groups, telephone surveys, or mail surveys. Questionnaires may either be sent in the mail, conducted as a self administered questionnaire, conducted as a telephone survey, as an interview process, face-to-face interviews, one-on-one interviews, or in a focus group. Questionnaires are administered to a sample of respondents selected from some population. Survey research can be employed for both descriptive and explanatory purposes and tends to be quantifiable. For a comprehensive overview of survey design, one would want to refer to Total Design Method (TDM) of Dillman (1978).

The interviewer facilitating the discussion would remain neutral. This is extremely important as this person should not impact the responses of the participant. Interview bias should be avoided to protect the objectivity of data collection as well as the reliability and validity of the study. Interviewers should be trained appropriately to facilitate the data collection process and to probe effectively. Questionnaires can be open-ended for responses or close-ended or a combination of both open-ended and close-ended questions. Standardization of the data collected is a strength of this research design. Survey research is also flexible, can be economical, and can also be used by another researcher for another
purpose (i.e., secondary analysis). Survey research tends to be weak on validity and strong on reliability.

Data and Statistical Analysis

Once the research design has been decided, a decision then needs to be made with regard to statistical analysis of the study. One question to answer: "Is the sample more than 25, under 20, does it yield a parametric or a non-parametric test?" If the instrument tends to be a standardized test, then a parametric test would be appropriate. In survey research, a non-parametric test would be considered appropriate unless a standardized test was being used as the instrument. For the purpose of this study, frequencies will be presented in table format.

Qualitative and Quantitative Research

Research design also tends to be driven by the characteristics and differences between qualitative and quantitative research. If the researcher's design is evolving, flexible, producing descriptive data, personal documents, field notes, or task analysis, and the sample is small and non-representative (theoretical sampling, so to speak), then the design would presumably benefit by a qualitative approach. Some researchers have handled such situations in quantitative ways (Whiting & Child, 1953). If the design tends to be more structured, formal, specific, and pre-determined, yielding quantifiable coding and operationalized variables that lend themselves to quantitative analysis (statistical analysis), then the design would be of a quantitative approach. In addition, if the researcher decided to employ a quantitative approach, the sample would tend to be larger, possibly stratified, may include random selection, control groups, and may also control for extraneous variables. It should be noted that some researchers see a continuity, rather than a discontinuity, between qualitative and quantitative research (Newman & Benz, 1998; Williams, 1991).
When the relationship with the subjects focuses on empathy, with an emphasis on trust and rapport building, the design would be qualitative. This study focused on a qualitative design due to the sensitivity of the topic and the need for participants to feel safe in sharing his/her referral story. Quantitative designs tend to be more short term, distant, and with a more subject-to-researcher focus. This is not always the case, however; for example, Williams and Klug (1996) used a four sampling period over 21 years in their longitudinal study regarding aging and cognitive functioning. In addition, when the researcher engages in quantitative research, the instrument tends to be an index, questionnaire, or an inventory that produces test scores and affords the researcher the opportunity to code the data into quantifiable form and to statistically analyze it. Some of the items in this study were coded and some of the data will be presented in table form representing frequencies. However, the thrust of the study is on the referral story as presented by the decision maker. The questionnaire for the study was structured in an open-ended as well as a close-ended format. However, the data analysis was ongoing, seeking emergent themes, employing analytical induction, constantly comparing the shared information with other cases. Quantitative data analysis seems to be deductive, statistical, and occurs at the conclusion of the data collection process, which was done at the conclusion of this study.

When the researcher’s focus is to understand a social phenomenon, qualitative research provides the researcher with the opportunity to engage in grounded theory. Grounded theory, as presented by Glaser and Strauss (1967), seeks to assist the researcher in understanding meaning; quantitative research begins with a hypothesis and seeks to replicate. This study is in search of meaning, the meaning of the referral process to the patient, the decision maker, and his/her families. HRRV wants to understand the referral process as it is perceived by the patient, his/her family, and the person making the decision to admit the patient to hospice care. In addition, hospice would like to understand why
patients admit to hospice care when they do, what the perceived benefits of hospice care are, and who initiates the referral process.

Because of the objectives hospice had for the study, qualitative research was the approach of choice. There are concerns with both approaches. Qualitative research tends to be more time consuming, data reduction may be difficult, procedures are not always standardized, it is difficult to use when studying large populations, and it may be problematic when seeking to show reliability (Bogdan & Biklen, 1992).

This section will discuss qualitative research presenting support for qualitative research as the approach of choice for this study. Qualitative research is often associated with both field research design and survey research design. This study used the telephone survey research design. Qualitative research tends to be either conducted for a descriptive or for an exploratory purpose. This study's purpose was descriptive and also became exploratory in nature.

Qualitative researchers often employ grounded theory (Glaser & Strauss, 1967) or symbolic interactionism (Blumer, 1969) as theories assisting the researcher in developing a rationale to understand the meanings, perceptions, purposes, goals, and constraints that individuals construct; his/her perception of his/her reality as it is experienced; and the meaning assigned to it (Goffman, 1959). Qualitative research is an inductive approach/process that assists with formulating or the generating of research questions/hypotheses that can be further explored based on the understanding of the observations discussed in the qualitative study.

Taylor and Bogdan (1984) define qualitative research as referring to research procedures which produce descriptive data; people's own written or spoken words and observations. The approach directs itself at settings and the individuals within those settings holistically; that is, the subject of the study, be it
an organization or an individual, is not reduced to an isolated variable or to an hypothesis, but is viewed instead as part of a whole. (p. 4)

According to Guy et al. (1987), qualitative research is research that "depends mainly on direct observation and descriptive analysis of social interaction and outcomes in specific social settings, sometimes relying on the intuitive skills of the researcher" (p. 453).

Rubin and Babbie (1993) define qualitative research methods as:
research methods that emphasize depth of understanding and the deeper meanings of human experience, which are used with the aim of generating theoretically richer, albeit more tentative observations. Commonly used methods include participant observation, direct observation, and unstructured intensive interviewing. (p. 701)

A second part of the study included a focus group with 18 social workers from a local hospital. The focus groups were conducted with the social workers as a form of triangulation in support of the study as a secondary component. The focus group design was based on suggestions by Krueger (1988).

Focus of Design

This study was a descriptive study focusing on a person's shared words, his/her "referral story" with regard to HRRV. The study did not reduce participants to isolated variables, nor to a hypothesis, but did view participants as part of the whole referral process. Descriptive analysis of the social interaction will be discussed; and oftentimes, as the writer, I did rely on my intuitive skills when probing. Emphasis was placed on the depth of understanding the participant's referral story as well as the meaning he/she attached to the process. An unstructured interview format was employed, and only when the decision maker did not share the full referral story as presented in the questionnaire did I solicit open-ended item responses from them. In addition, Rubin and Babbie (1993) speak to qualitative research as being "non-numerical examination and interpretation of
observations for the purpose of discovering meanings and patterns of relationships" (p. 701), a clear concern of this study.

Qualitative interviewing was the technique utilized for this study. Patton (1990) identifies three forms of open-ended interviewing used in qualitative research. The informal conversation interview is the most open-ended form, where the interaction tends to be unplanned and not anticipated. The open-ended form was not used, as all of the participants were aware of the fact that they would be contacted, had they given written consent to be contacted. The general interview guide approach, according to Patton, is a more thought out, more planned, as well as more structured interview process than the informal conversational interview process. The interview guide provides a general outline form of topics and issues to be covered in the interview. This format is flexible, as is the informal conversation interview; however, as the interviewer guides the process, this form allows for adaptation should a response facilitate a question not on the outline.

Standardized, open-ended interviews are structured, written exactly the way they are to be asked, in the same sequence each time. Probes are limited unless the researcher is highly skilled. If the researcher is a skilled interviewer, there is opportunity for more flexibility in probing. In addition, questions are logically arranged and sequenced. This study tended to be a combination of this form and the general interview guide; however, the decision maker was allowed the opportunity to share his/her referral story first. If the questions on the questionnaire were not responded to during this referral sharing opportunity, responses were then solicited. In addition, probing was employed when appropriate. Interview responses were recorded and coded on each of the individual participant's questionnaires. Participants were given an identifying number and responses were discussed confidentially. Running notes were often used when the participant shared his/her referral story. When I repeated the participants' referral stories to them, I would
share their words as well as my understanding of their stories, seeking clarification where appropriate, filling in the journal entry for accuracy in as much detail as possible.

Qualitative research studies produce qualitative data, and qualitative data are not easily reduced to numbers. In analyzing qualitative data, researchers seek emergent themes as well as similarities and dissimilarities in recorded interviews. Often qualitative data are reported in categories of nominal variables (gender, age, ethnicity, religious affiliation, etc.). Some of these data will be presented in table form. In addition, the responses will also be quantified and statistically analyzed utilizing descriptive statistical techniques, summarizing the sample observations. Frequency distributions are presented in table form in Chapter IV.

Because of my closeness to the topic, I was sensitive to some of the "logical pitfalls" Kahane (1980) and Gilgun (1994) discuss as needing to be avoided when engaging in qualitative research. I was concerned with the issue of selective perception, as I did not want to see only what I wanted to see when analyzing the data, or to become desensitized to new themes. I was also clear about avoiding provincialism, or making sense of the responses only from my point of view, of being ethnocentric. I also was concerned with "going native" or identifying too closely with each individual story. Gilgun discusses the issue of personal reactions and how they can impact the analysis of the data, especially if the researcher over identifies with the participant or has a strong personal reaction to the topic. I was quite cognizant of this "logical pitfall." In addition, I continually reminded myself to avoid hasty conclusions and not to interpret the data too quickly.

Qualitative research was the procedure of choice, because it afforded me the opportunity to utilize a more flexible design that would produce descriptive data from a smaller, non-representative sample. The data analysis was ongoing; I was able to continually discover emergent themes, engaging in inductive analysis, constantly
comparing responses and referral stories. This study will hopefully describe the referral process as perceived by the decision maker as well as generate questions for future exploration. The purpose of this study was to describe the relationship between hospice, the decision maker, the referral process, who initiates the referral process for the family, the decision maker's understanding of the referral process, as well as "Why now?," and perceived benefits of hospice care. The unit of study was the perceived decision maker. The method of non-probability sampling as described by Patton (1990) would be critical incidents. It was purposive sampling, as the sample was selected for the purpose of providing the most comprehensive understanding of the issue being studied. The sample was a census of decision makers experiencing the hospice referral process because of the terminal diagnosis of an illness, the critical incident. Grounded theory was the methodology of choice and symbolic interactionism was the theoretical paradigm that guided the study. Symbolic interactionism looks at the interactions that occur between the individuals in the social setting, seeking to understand individuals' responses to the interaction, their perception of the event, their interpretation of the event, and the meaning they attached to it. One of the rationales for this study was to seek to understand the meaning attached to the referral process for the decision maker.

In conclusion, qualitative research provides a depth of understanding and is especially valuable in sensitive research areas. It is valuable in assisting with the discovery of emergent themes, patterns, and developing future avenues of exploration. The next chapter will present the study's findings.
CHAPTER IV
RESULTS

The decision making process for terminal and end of life care presents the patient, family members, social service professionals, and health care providers with challenging scenarios, one of which could include the decision to seek hospice care. We live in a society that has been characterized as death-denying. Medical care at the end of life is often typified by high technology, aggressive treatment modalities, clinical trials, and the search for hope-giving options. It is within this emotionally charged situation that researchers seek to understand the decision making process for end of life situations. The decision making process also tends to be complicated by a plethora of structural constraints that simultaneously impact the decision making process. These contexts include (but are not limited to) the psychology of the patient, family members, physicians, and other health care team members; the reimbursement environment; and accepting the patient’s terminal diagnosis.

The goal of this study was to untangle the decision making process so that hospice personnel could develop an understanding of how patients and their families tend to gravitate to seek hospice care. This information can also assist hospice more effectively in the promotion of services to those patients who are appropriate for hospice care and for hospice services.

The data for the study were collected from February 1998 through September 1998. Hospice of the Red River Valley provided names and telephone numbers of individuals who contacted hospice regarding the possibility of seeking hospice care. These individuals, who tended to be primarily family members, were contacted by telephone and
invited to participate in a telephone interview. The response rate for this method was 100%. Rather than drawing a sample, the approach was to do a census of the first 100 inquiries that were made.

All potential research participants signed a consent form prior to being contacted. The consent form was presented to the potential participant by a hospice representative who did meet with the patient and his/her family for the initial hospice informational meeting. In some cases consent forms were not provided and potential respondents were not recruited. This delayed the completion of the study but introduced no known bias into the participant group. The participant in the study was the identified perceived decision maker who was often not the identified care giver. In addition, three of the identified perceived decision makers chose not to participate in the study but had other family members participate as they felt that the other family member would be able to respond to the items on the questionnaire more accurately than they would. In these instances, both individuals signed the consent to participate form and the person who did participate was a daughter of the patient.

Data from a focus group with social workers from an area hospital will also be discussed as it relates to the primary study. Focus groups were included as a secondary study in support of the data obtained from the participants in the primary study. Participants were recruited as volunteers, with the only incentive for assisting with the study being one of an altruistic nature. All of the full time social workers in the hospital were invited to participate in the focus group. Findings will be discussed as a form of triangulation at the end of this section.

Interview Data

The first interview question determined the primary care giver for the patient. In the majority of cases, the primary care giver was an individual; however, long term care facilities were also frequently mentioned. Table 1 presents the data from this question.
Table 1

Care Giver for Patient

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wife</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>Daughter</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>Husband</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>Son</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Villa Maria</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Patient</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Bethany Homes</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Rosewood</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Manor Care</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Moorhead Health Care</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Mother</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Viking Manor</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Niece</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Sister</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Home health care</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Patients must have a primary care giver to receive hospice care or a plan in place to have a primary care giver prior to hospice admission. The data in Table 1 show 25% of the patients were cared for by a wife, 18% were cared for by a daughter, 14% by a husband, and 9% by a son. In total, nuclear family members accounted for 68% of the care givers.

Long term care facilities are listed as the care giver for 22% of the patients. The patient was the care giver in 5% of the cases with the remaining 5% of the patients naming a sister-in-law, niece, sister, or home health care agency as the care giver.
The next question asked who the perceived decision maker was when seeking hospice care. This is the individual or individuals making or assisting in making the decision for selecting hospice care. Table 2 presents data from this question.

Table 2

<table>
<thead>
<tr>
<th>Decision Maker for Hospice Care</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter</td>
<td>31</td>
<td>31</td>
</tr>
<tr>
<td>Wife</td>
<td>22</td>
<td>22</td>
</tr>
<tr>
<td>Son</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Patient</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Husband</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Niece</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Sister</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Friend</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Mother</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Nephew</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2 shows that daughters (31%) were most frequently mentioned as decision makers for hospice care. A total of 22% of decision makers were wives, 15% were sons, 10% were patients, and 10% were husbands. Nuclear family members, excluding the patient, account for 78% of the decision makers. These results are important because it appears that the care giver most frequently identified, wives (25%), and the perceived decision maker, daughters (31%), were not the same person. Gochman and Bonham (1988) reported that the final decision maker was identified as the care giver in 66.38% of the cases they studied.
Table 3 presents responses from a question asking who began the discussion with regard to seeking hospice care. Table 3 shows that 32% of those who began the hospice discussion were physicians and another 26% were social workers. Nurses accounted for 19% of which 14% were long term care nurses. Nuclear family members included 13% of the cases. Overall, 81% of those who initiated the discussion were professionals involved in the direct delivery or support of medical care; this includes physicians, long term care nurses, nurses in hospital settings, nurses in clinics, medical social workers, long term care social workers, physician assistants, and also home health care agencies. Because of this circumstance, focus groups were facilitated with medical social workers in a hospital seeking to understand the social worker role in the referral process.

Table 3 lists individuals who began the discussion of hospice care but some of those individuals were acting under the direction of another person. Table 4 indicates those individuals who used "intermediaries" to begin the discussion of hospice care. For example, the participant in the study may initially state that a social worker began the discussion and after further discussion, he/she may state that the physician told the social worker to have the family contact hospice; therefore, the physician in actuality began the discussion to seek hospice care. This information is important because it provides a more complete picture of the communication process involved with hospice decision making.

Table 4 presents data on who used intermediaries. Table 4 shows that four physicians used intermediaries as did six social workers, one hospice nurse, one daughter, and one long term care Certified Nursing Assistant. The data indicate that a physician may suggest to a social worker that now would be an appropriate time to inform the family of hospice services as an option to care.
Table 3

Who Began the Discussion Regarding Hospice Care?

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>MeritCare physician</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>LTC nurse</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>MeritCare social worker</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Daughter</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Dakota Clinic physician</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Independent physician</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Dakota Clinic social worker</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Wife</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Manor Care social worker</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Roger Maris social worker</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Friend</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Rosewood social worker</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Moorhead Health Care social worker</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Villa Maria social worker</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Son</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Husband</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Dakota Heartland social worker</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Manor Care physician assistant</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Oasis</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Clay County Social Services</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Elim social worker</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>MeritCare nurse</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>MeritCare physician assistant</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>VA social worker</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Did not know</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>
Table 4

Individuals Who Used Intermediaries to Begin Discussion

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Dakota Clinic social worker</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>MeritCare social worker</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Hospice nurse</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Daughter</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Long term care CNA</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Did not use intermediary</td>
<td>87</td>
<td>87</td>
</tr>
</tbody>
</table>

The respondents were also asked to indicate the date that hospice was introduced to them. Hospice was contacted to determine the actual date of contact with the patient and the date the patient was actually admitted. These data are important because it sheds light on the issue of decreasing length of stay in hospice. Specifically, patients and decision makers tend to view hospice care as death bed care. This is because many do not feel that he/she were imminently dying so he/she felt he/she had more time to live and did not want hospice until the end. In addition, some were already in a nursing home and were not aware that hospice would provide care within the long term care facility. For example, as several decision makers stated:

We did not realize hospice went into nursing homes . . . I never thought hospice would be available to us because mother is in the nursing home . . . I wish I would have known sooner . . . We knew we could call hospice on our own but we did not know hospice went into nursing homes so we never called . . . assumed that since we were in the nursing home that we did not have a chance to have hospice.
In addition, many families did not know that Medicare paid for hospice services. The difference between the referral contact and the actual date of admission is presented in Table 5.

Table 5

How Many Weeks Before Admittance Was Hospice Care Considered?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>One week or less</td>
<td>65</td>
</tr>
<tr>
<td>Two weeks</td>
<td>12</td>
</tr>
<tr>
<td>Three weeks</td>
<td>2</td>
</tr>
<tr>
<td>Four weeks</td>
<td>2</td>
</tr>
<tr>
<td>Five weeks</td>
<td>1</td>
</tr>
<tr>
<td>Six weeks</td>
<td>4</td>
</tr>
<tr>
<td>Seven or more weeks</td>
<td>7</td>
</tr>
<tr>
<td>Were not admitted (died, etc.)</td>
<td>7</td>
</tr>
</tbody>
</table>

The data in Table 5 show that 65% of the patients considered hospice care one week before being admitted. An additional 12% considered hospice care two weeks prior to admittance. The remaining 16% of those admitted considered hospice care for three or more weeks prior to being admitted. A total of 7% were not admitted to hospice because he/she died before he/she could be admitted or decided not to pursue hospice care. These data suggest the issue related to the decline in ALOS, as it appears the patient and his/her family in this study contacted hospice with few weeks remaining indicating hospice was being used for end of life care.

A follow-up question to this was "Why now, why is hospice care being considered at this time?" Responses to this question included but were not limited to "I guess because the nurse brought it up at this time... the doctor told us to call, not getting any better... the social worker suggested it [use of intermediaries]. Other responses included "Looking
ahead... We just found out she had cancer and that she had little time left to live." Several of the participants reported that they were contacting hospice now because they were told to do so by either a physician or a social worker. Other responses included:

I want to stay at home... do not want to be alone and I need the 24 hour crisis care... the choice was hospice or else a nursing home, choose hospice... just worn out; need respite, need more help... no treatment left to be done... need help with bathing and volunteers to come in and stay with him so I can get out... want to know them before I die... dad is not turning around, just wants to die... was not getting any where with any one else... could not qualify before, qualify now for Medicare reimbursement.

The respondent was also asked if there were individuals other than those listed in Table 2 involved in the decision making process for hospice care. Table 6 presents findings from this question. The data in Table 6 show that the patient was involved in 25% of the decisions and physicians were involved in 13%. Nuclear family members were involved in 34% of the cases. Extended family members were involved in 8%, friends 2%, and other health care professionals 6%.

The respondents were then asked who they perceived to be involved in the final decision. This question was asked as a form of triangulation to verify who was actually involved in the final decision. By using more than one method of data gathering, it was hoped that the findings would increase the reader's understanding of the hospice referral process. It is possible that those involved in the initial sharing of information were not those who played a part in the final decision to seek hospice care. Table 7 presents data from this question.
Table 6

Other Individuals Involved in the Hospice Decision Making Process

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>25</td>
</tr>
<tr>
<td>Physician</td>
<td>13</td>
</tr>
<tr>
<td>Son</td>
<td>13</td>
</tr>
<tr>
<td>Daughter</td>
<td>12</td>
</tr>
<tr>
<td>Wife</td>
<td>5</td>
</tr>
<tr>
<td>Husband</td>
<td>4</td>
</tr>
<tr>
<td>Friend</td>
<td>2</td>
</tr>
<tr>
<td>Social worker</td>
<td>2</td>
</tr>
<tr>
<td>Sister</td>
<td>2</td>
</tr>
<tr>
<td>Mother</td>
<td>1</td>
</tr>
<tr>
<td>Nurse</td>
<td>1</td>
</tr>
<tr>
<td>Hospice nurse</td>
<td>1</td>
</tr>
<tr>
<td>VA social worker</td>
<td>1</td>
</tr>
<tr>
<td>MeritCare social worker</td>
<td>1</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>1</td>
</tr>
<tr>
<td>Nephew</td>
<td>1</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
</tr>
<tr>
<td>Brother</td>
<td>1</td>
</tr>
<tr>
<td>Son-in-law</td>
<td>1</td>
</tr>
</tbody>
</table>

Note. Percentages total to more than 100% because of multiple responses.

Percentages reported in Table 7 represent more than 100% because of multiple responses. The data show that in 41% of the cases the patient was involved. Other final decision makers included daughters (36%), sons (20%), wives (19%), physicians (14%), and husbands (7%).
Table 7

**Individuals Involved in the Final Decision Making Process**

<table>
<thead>
<tr>
<th>Individual</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>41</td>
<td>41</td>
</tr>
<tr>
<td>Daughter</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Son</td>
<td>20</td>
<td>20</td>
</tr>
<tr>
<td>Wife</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>Physician</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>Husband</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Niece</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Mother</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Sister</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Father</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Nurse</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>LTC social worker</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>MeritCare social worker</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Nephew</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Brother</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Hospice nurse</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Social worker</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

The next question focused on awareness of hospice and stated, "Had you heard of hospice prior to the patient's illness?" Table 8 presents data from this question. The data in Table 8 show that awareness is high, as 96% had heard of hospice.
Had You Heard of Hospice Prior to the Illness of the Patient?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>96</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
</tr>
</tbody>
</table>

The next question asked if the patient received any information about hospice during the illness. Table 9 presents data from this question.

Did You or the Patient Receive Any Information About Hospice During the Illness?

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>36</td>
</tr>
<tr>
<td>No</td>
<td>62</td>
</tr>
<tr>
<td>Do not know</td>
<td>2</td>
</tr>
</tbody>
</table>

The data in Table 9 show that only 36% of the respondents received information and 62% did not. An additional 2% did not know. Perhaps these data point to core problems that plague the relationship between health care providers and chronically ill patients. These are the enduring problems of when to tell a patient that their time is limited and so forth. There is a reluctance to communicate information that is perceived as destroying hope so the result is a lack of information about the benefits of hospice services. Information is then provided at the 11th hour when the patient is clearly dying and death bed care is the primary service that is needed.

Those who indicated "yes" to the previous question were asked to indicate the source of the information that they received. Table 10 presents the data from this question.
Table 10
Source of Information About Hospice

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brochure</td>
<td>34.9</td>
<td>15</td>
</tr>
<tr>
<td>Hospice</td>
<td>32.6</td>
<td>14</td>
</tr>
<tr>
<td>Nurse</td>
<td>16.3</td>
<td>7</td>
</tr>
<tr>
<td>Physician</td>
<td>14.0</td>
<td>6</td>
</tr>
<tr>
<td>Friend</td>
<td>9.3</td>
<td>4</td>
</tr>
<tr>
<td>Clergy</td>
<td>4.7</td>
<td>2</td>
</tr>
<tr>
<td>Hospital literature</td>
<td>4.7</td>
<td>2</td>
</tr>
<tr>
<td>Health care professional</td>
<td>2.3</td>
<td>1</td>
</tr>
</tbody>
</table>

Percentages represented in Table 10 equal more than 100% because of multiple responses.

The results in Table 10 show that 34.9% of those who received information were given a brochure, and 32.6% received information directly from hospice. (These were people who spoke directly with a hospice representative at the hospital.) An additional 32.5% received information from a health care professional (nurse, physician, etc.), 9.3% received information from a friend, 4.7% clergy, and 4.7% received hospital literature about hospice.

When asked the question "Was hospice used?," 71% reported they had admitted their family member to hospice care. Table 11 presents data on the admittance status of the patient. As reported below, at the time of the interviews 71% had been admitted and 19% had not. Those 19% were not yet sure if they were ready to discontinue their current treatment and some had not yet started to consider hospice care and were engaged in fact finding. A total of 4% were still in the process of considering hospice care and 6% died before they could make a decision. Note that when the date of referral call and admission date were received from hospice that hospice showed that 7% of the referrals did not admit.
It is expected that this figure differs because the figure reflects all of hospice referrals and not just those who participated in the study. Of those who were considering hospice (4%) or who were not admitting (19%), when asked why, they reported, "Just wanted basic information"; "no insurance to cover hospice and are not Medicare eligible at this time, want to continue with the aggressive treatment"; "the hospice medical director will not allow it, say that chemotherapy is aggressive treatment and we see it as pain control"; "we do not feel we need it."

Table 11

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>71</td>
<td>71</td>
</tr>
<tr>
<td>No</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>Considering hospice</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Died before decision could be made</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>

There were many barriers reported when seeking hospice care. Several surrounded the issue of Medicare and being Medicare appropriate. Medicare regulations indicate that a patient is eligible to receive Medicare hospice benefits if a physician certifies that the patient has six months or less to live, if the disease runs its expected course. This is the gatekeeping function of the physician. Because physicians are the primary gatekeepers for so many types of health care, patients may have the perception that a physician's approval is required to seek hospice care. You do not need a physician's approval to seek hospice, but you do need a physician to document life expectancy. Some of the responses included but are not limited to:

They are not Medicare appropriate now, would have to discontinue all other services and only use the hospice benefit... would have to discontinue other
treatment options to be Medicare eligible. Hospice does not provide enough help, limited benefits, Medicare is constraining, want to slap government officials, it's a shame. We have someone sitting in a chair making decisions on who is eligible and for what. We have a 70-year-old man who won't eat, is in a diaper, cannot control his bowels, dying of cancer, and his care is limited because of Medicare. Doctor insists chemotherapy is palliative, but hospice does not see it that way; the hospice medical director says no to hospice until she is off of chemotherapy, when chemotherapy is not seen as a cure—it should be allowed—is juxtaposed to what hospice philosophy is all about. We are very angry with the hospice care concept and reimbursement. The hospice social worker was very condescending. Mother was not appropriate insurance wise; insurance does not have a hospice benefit. Mother had to be asked to leave the hospital and then we could apply for Medicaid to cover hospice care.

Several reported statements resembling this one: "Have to drop all other Medicare services to be on hospice so that Medicare will cover the care and are not going to do this at this time."

Other barriers reported by participants to seeking hospice care included but were not limited to:

The doctor was not supportive of hospice. Did not know she was dying. Thought hospice equaled cancer. She did not know she could just call hospice. Hospice is too intrusive. Did not receive any information about hospice, thought it was for death bed care and only for those with cancer.

Other responses included:

No one had said mom was dying; I did not like the fact that the only time I found out mom was dying was because of the hospice brochure that had been handed to me. When the doctor suggested hospice, I did not think mom was appropriate.
because he had not said she was dying and hospice is for those who are dying... I was upset with a hospice person who was quite loud and vocal about using hospice, too pushy, but we had to have hospice to get the second unit of oxygen because Medicare would not pay for the second unit unless we had it [hospice]...

We were very leery of hospice care because of our experience with hospice seven years ago when we had it for my brother... I assumed that since we were in the nursing home that we did not have a chance to have hospice.

This next question was designed to determine how many decision makers were aware of the fact that they could self refer. Table 12 presents data on awareness of this self referral option.

Table 12

<table>
<thead>
<tr>
<th>Awareness of Decision Makers to the Fact That They Could Self Refer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency</td>
</tr>
<tr>
<td>----------</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

Only 25% of the decision makers were aware of the self referral possibility; 75% of the respondents were not aware of this option and actually tended to report believing that they needed to have a physician make the initial referral contact for them. Of the respondents who did know they could self refer, when asked where they received the information, they tended to report receiving the information most frequently from a friend or relative (24%) who had previously learned of hospice because of a cancer related illness. In a way these and other findings in this study are not surprising at all. After all, we are dealing with the issue of death and decision making and "consumer information seeking" does not follow
the same aggressive channels as might be the case for the purchase of other products and services. This puts a special burden on service providers to try to cut through these deep-seated inhibitors, anxieties, fears, etc., so that information on care options may be processed.

When asked why they did not believe they could self refer, participants reported believing that they could not just call without being told to call by a physician. Some of the reported comments include but are not limited to:

I would not have thought of it . . . just called for information, they did not tell me anything about the referral process . . . I had no clue I could just call . . . many shared that they thought I had to wait for a doctor to refer me . . . did not know Medicare would cover hospice . . . got a brochure from the social worker and verbal information, but I did not know I could call on my own . . . why is there not more information about hospice? . . . Had heard vaguely about it, did not apply to me so I did not pay any attention, now I need it and I did not know how to access it . . . my neighbor told me it was only for cancer and that a doctor had to send you there, so I only thought about hospice with cancer.

Other comments included:

Did not know or I would have much sooner . . . would not have thought of hospice with mother in the nursing home . . . I did not realize all of the benefits, wish I would have known I could have called before the social worker brought it up, we could have used it much sooner . . . I am confused as to why the doctor did not mention hospice earlier . . . we were at end of life . . . there was such a delay . . . Had I of known I could call myself, I would have a lot sooner . . . was so frustrating, just added to the feelings of powerlessness, is awful.
Additional comments included:

Never thought we could just call, thought we needed to have a doctor involved . . . never knew we could call on our own for information or anything, I have sat and thought how I could have used this two months ago . . . and [another participant reported] . . . never gave a thought to it because we did not need it . . . was not aware that hospice went into nursing homes so we would have never given it a thought.

Those who indicated "yes" to the previous question were asked how they learned that self referral was an option. Table 13 presents data from this question.

Table 13

Source of Information About Self Referral

<table>
<thead>
<tr>
<th>Source</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relatives</td>
<td>24</td>
<td>6</td>
</tr>
<tr>
<td>Hospice</td>
<td>20</td>
<td>5</td>
</tr>
<tr>
<td>Unsure</td>
<td>20</td>
<td>5</td>
</tr>
<tr>
<td>Physician</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>Brochure</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Friend</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Newspaper</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Book</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Magazine</td>
<td>4</td>
<td>1</td>
</tr>
</tbody>
</table>

Percentages for Table 13 totaled more than 100% because of multiple responses given. Of the 25% who were aware of self referral most (24%) had heard of this from relatives and 20% had heard directly from a hospice representative. An additional 20% were unsure/did not remember, 15% received that information from a physician, and 8% received it from a brochure. A variety of other sources were mentioned once.
The decision makers were also asked if the patient was participating in a clinical trial. Table 14 presents data from this question.

Table 14

<table>
<thead>
<tr>
<th>Involvement in Clinical Trial</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>No</td>
<td>98</td>
<td>98</td>
</tr>
</tbody>
</table>

The results show that only 2% of the 100 patients were involved in clinical trials. These data are undoubtedly reflective of the age of the patients in this study. Clinical trials give hope and these patients are older and at the final stages of their disease process.

Table 15 through Table 19 present data regarding patient demographics. Table 15 presents data on the sex of the patient population studied.

Table 15

<table>
<thead>
<tr>
<th>Sex of Patient</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>44</td>
<td>44</td>
</tr>
<tr>
<td>Female</td>
<td>56</td>
<td>56</td>
</tr>
</tbody>
</table>

A total of 44% were male and 56% were female.

Table 16 presents data on age. Only 2% were under the age of 39 with both of those being infants under 2 months of age. An additional 9% were between 40 and 59. The data also show that 18% were 60 to 69 with the remaining 71% 70 and over.

Eighty-nine percent of the cases in the study were between the ages of 60 and 103.
Table 16

Age of Patient

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 19</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>20-29</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>30-39</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>40-49</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>50-59</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>60-69</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>70-79</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>80-89</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>90-99</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>100 and over</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 17 presents data on the primary physician for these patients. Physician area of specialty is presented in this table. It appears that physicians specializing in internal medicine were identified by the perceived decision maker as the primary physician for the patient in 39.6% of the cases; oncology was reported as the primary physician specialty in 26.4% of the cases. Family practitioners were identified as the primary physician in 15% of the cases. Other physicians/specialists identified included cardiologists in 4.5% of the cases; neurologists and gastroenterologists each in 3.6% of the reported cases; and pediatricians, rehabilitation physicians, and vascular surgeons were reported as being the specialist in 1.8% of the cases, respectfully.

Table 18 presents data on the primary disease that made the patient hospice appropriate. Cancer was the most frequent diagnosis (55%) followed by chronic obstructive pulmonary disease (12%), chronic heart failure (11%), failure to thrive (8%), and Parkinson's (3%). Eleven other diagnoses were each mentioned once.
Table 17

**Patient’s Primary Physician**

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal medicine</td>
<td>39.6</td>
<td>21</td>
</tr>
<tr>
<td>Oncology</td>
<td>26.4</td>
<td>14</td>
</tr>
<tr>
<td>Family practice</td>
<td>15.0</td>
<td>8</td>
</tr>
<tr>
<td>Cardiology</td>
<td>4.5</td>
<td>3</td>
</tr>
<tr>
<td>Neurology</td>
<td>3.6</td>
<td>2</td>
</tr>
<tr>
<td>Gastroenterology</td>
<td>3.6</td>
<td>2</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>1.8</td>
<td>1</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>1.8</td>
<td>1</td>
</tr>
<tr>
<td>Vascular surgery</td>
<td>1.8</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 19 presents data on marital status. Nearly one half (49%) of the patients were currently married, 18% were single (divorced or reported never having been married), and 33% were widowed.

Table 20 presents data on residence for these patients. A total of 63% resided at home, 36% resided in long term care facilities, and one in assisted living and another reported as being in transition.

Participants were then asked what he/she perceived as being benefits to seeking hospice care. It seems that level of satisfaction with hospice care delivered by HRRV is quite high. It also seems that hospice is contacted when physicians perceive family members appearing to be exhausted and when the patient has deteriorated to a point where increased care is necessary. Support, comfort care, volunteer visits, and the information received during communication with hospice representatives were also reported as having increased value to the perceived decision maker and his/her family. In addition, Medicare
reimbursement was discussed as being both a benefit and also as a challenge because of the admission criteria used in assigning appropriateness when seeking hospice care.

Table 18

**Disease That Made Patient Hospice Appropriate**

<table>
<thead>
<tr>
<th>Disease</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>55</td>
<td>55</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Chronic heart failure</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Failure to thrive</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Parkinson's</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Chromosome abnormality</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cirrhosis of the liver</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>End stage dementia</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>End stage heart disease</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Gangrene</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Kidney infection</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Myelodysplastic</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Paralyzed bowel</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Primary lateral sclerosis</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Stroke</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Trisome 18</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Participant comments with regard to hospice care reflect a high degree of respect for HRRV. Some of the comments included but are not limited to:

A major benefit is pain management, symptom control ... the physical benefits are important, comfort, care, the concern hospice has for all of you ... there was someone by her side if we could not be there ... it allowed her to die at home ...
the crisis care, 24 hour care was important... someone to talk to, counseling was helpful... there was ongoing support, someone to talk to and count on... help with the oxygen... kept the medications in order, helped with baths.

Table 19

Marital Status of Patient

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td>Single</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>Widowed</td>
<td>33</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 20

Residence of Patient

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>63</td>
<td>63</td>
</tr>
<tr>
<td>Bethany Homes</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Villa Maria</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>Manor Care</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Rosewood On Broadway</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Moorhead Health Care</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Viking Manor</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Elim Home</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Eventide</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Evergreens</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>In transition</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
Other comments included:

They assisted with the Medicare reimbursement process, paid for medications, and equipment once he was on Medicare... support services were helpful; I was worn out, volunteers were wonderful... the education was so helpful, they let you know what was going on... hospice was increased care for us at the nursing home... [and, finally, another benefit referred to often was] the follow-up bereavement care will be quite helpful I am sure.

Summary of Interview Data

Findings from this study suggest that patients are referred to hospice by physicians most often (32%), social workers (26%), and nurses (19%). A majority of patients (65%) are referred to hospice within one week of finding out the terminal prognosis of his/her illness. In addition, the person identified as making the final decision to seek hospice care tends to be the patient who is not the identified perceived decision maker who signed the consent to participate form for the study; nor is the care giver reported to be the perceived decision maker. The care giver reported most often tends to be the wife (25%) or a LTC facility (37%). Also, participants were not aware of the fact that they could self refer in 75% of the cases. Participants tended to believe that he/she needed a physician to initiate the referral process for them. The findings show that awareness of hospice is quite high as is level of satisfaction with hospice care. Unfortunately, only 36% of those who had heard of hospice reported receiving any information about hospice during the illness.

Focus Group Data

A second phase of the study involved data gathering from social workers. A 60 minute focus group was conducted at a local hospital with a group of 18 social workers. Participants were first given a survey form with six questions on it (Appendix C). Responses to the survey were discussed as well as additional topical areas. Focus groups were conducted with the social workers at a local hospital as a form of triangulation in
support of the study as a secondary component. According to Coldeway (1988), triangulation is one method a researcher can employ to "enhance the validity of research findings" (p. 51). The contact for arranging the focus group was the Social Service Manager at the hospital.

Development of the instrument and the facilitation of the focus group was based on Krueger (1988). The focus group format was employed for this data gathering process, because it was felt that as participants listened to the responses of one another that his/her response may trigger a response in another participant, and, in addition, one participant's response may influence another's. Focus groups tend to be a dynamic process. Participants are interacting with others in a natural setting, an environment conducive to information sharing. Attitudes as well as perceptions tend to be developed based on our interactions with others. According to Krueger, part of the intent of the focus group format is to "promote self disclosure among participants" (p. 23). For this to occur, it is important to create an environment where all participants feel heard, safe, and that he/she have permission to disclose. It was important for all participants to understand that there are no right or wrong answers, that the purpose was to encourage alternative explanations, to gather information through skillful probing, and for all participants to understand that they were invited to participate in the focus group based on his/her similar experience with hospice. In addition, participants were encouraged to understand that their perception with regard to the questions and the hospice concept may have similarities, but also differences may prevail. By creating a permissive environment conducive to information sharing it was hoped that all participants would feel comfortable in sharing their opinion, even if those opinions differed from the majority.

The focus group method is a form of qualitative research design utilizing an open ended question format. Focus groups provide data of a qualitative nature obtained from a focused discussion. Questions were designed to illicit information with a specific purpose
in mind. The purpose of the focus group was to have the social workers share their perception of hospice benefits, barriers to seeking hospice care, as well as obstacles they perceived as delaying the decision to seek hospice care. The focus group was facilitated in support of some of the findings from the primary study for my dissertation. It appeared that social workers were instrumental in the decision making process for the patient and his/her family when seeking hospice care. Social workers were the group of choice as opposed to physicians and nurses as the Social Service Manager negotiated the entry for me because of a pre-existing relationship; she is a student of mine, and it was felt that nurses and physicians, due to the schedule they maintain, would not be able to be coordinated. Due to time constraints, a survey was not an option.

When facilitating the focus group with the social workers, special attention was paid to the perception of each social worker and, when appropriate, probing occurred to illicit elaboration of an item. As the facilitator, I found myself guiding the questionnaire process, probing where appropriate, actively listening, moderating, observing the process as well as the participants. Analysis of the data was an ongoing inductive process, seeking to understand the referral process, identifying emergent themes, and also seeking triangulation.

Running notes were maintained of both the participant responses as well as employing task analysis, noting participant non-verbal mannerisms as well as facilitator notes. Shifts were recorded in the process, as well as any other information deemed relevant at the time. The session was also audio taped as a back up measure.

Question one asked the participants the following: "Approximately how many individuals have you worked with in the past 12 months who have considered hospice care?" Responses ranged from 0 to 70 for a total of 331 individuals.

Question two asked "What do you see as the major benefits of hospice care to the patient and family?" This question was created in support of the question asked of the
decision maker in the primary study: "What benefits do you perceive as being available to you because of hospice care?" In summary, emergent themes that tended to reoccur from item two were most concerned with pain management, pain control, hospice being defined as a service to the entire family, the financial aspects of hospice care (Medicare), the patient being able to die at home, comfort measures and the bereavement follow-up, after care available for the patient's family. These same themes were discussed as being of importance to the perceived decision maker in the primary study.

The third question asked the social workers participating in the focus group was "What factors had led hospice appropriate patients away from hospice care?" This question was developed based on the data obtained from the primary study. Many of the decision makers reported that they were often discouraged by the reimbursement process as well as a lack of information sharing about hospice care and the services provided by hospice in general. In an effort to understand the decision maker's comments, this item was identified as being paramount to the study. Social workers also reported that reimbursement tended to be a barrier for families seeking hospice care; families reported to the social workers that they did not understand the Medicare reimbursement process or the eligibility criteria involved in admission to the hospice benefit. Social workers also reported that some family members also did not have a hospice benefit on his/her insurance plan. Other reported emergent themes focused on a lack of primary care giver, denial, and the unwillingness of non-hospice staff to discuss the patient's terminal illness. The issue of denial has relevance to the primary study as the majority of participants were over 60 years of age (89%). It appears that those younger sought more aggressive treatment options and also were not willing to "give up" (social worker quote) and tended to not participate in the primary study.
Question 4 required a "yes" or "no" response and asked the following of the participants: "Do you think there are more patients who should consider hospice care?" All of the participants in the focus group responded "yes" to this question.

Question 5 asked "What factors tend to delay the decision to begin hospice care?" This item was included because of the average length of stay (ALOS) reported by hospice for hospice patients. As suggested by the primary study, ALOS for HRRV patient census is and has been declining. To understand this issue better, this question was asked of the social workers and responses to this question supported some of the data from the primary study. Physicians were reported by the social workers as not always being supportive of the hospice concept, or tended to not be supportive of hospice until the patient required death bed care. It appeared that the physician wanted to exhaust all aggressive treatment options for the patient. Other reasons for this lack of support included the physician not being certain of the trajectory of the terminal illness, the criteria for reimbursement (Medicare as well as other insurance plans), a lack of education as to the services, as well as the patient him/herself not being willing to stop treatment.

The final question asked "Are there any other things that can help us understand the decision making process of selecting hospice care? Please describe." This question was asked to assist the primary study with understanding what the information was that was actually being shared with the patient and his/her family when seeking hospice care. Themes that emerged concerned the physician's timing in sharing the terminal illness with the patient and his/her family as well as the information that was actually shared. Patients are not always told that they are terminal, but they are provided a variety of aggressive treatment options for the illness. Other themes consisted of a physician's willingness to share the terminal prognosis with the patient, and as reported by some of the participants in the primary study, family members may know the patient is dying, but the patient may not have been told this information directly by the physician. In addition, social workers report
that if the physician does not want hospice involved, patients tend to not seek hospice care. In addition, as reported by the social workers, most patients do not want to "give up" and view hospice as equating with death, with "giving up." Finally, social workers also indicated that families are not aware of all of the services available to them through hospice care.

The final chapter, Chapter V, will discuss the summary, conclusions, and recommendations of the study.
CHAPTER V
SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary of the Study

Purpose of the Study

The purpose of this study was to describe the referral process for families seeking hospice care. Hospice of the Red River Valley, a health care provider, was interested in knowing if individuals participating in the study were aware of the fact that they could self refer (i.e., to contact hospice without a physician suggesting it to them). HRRV also wanted to understand the question "Why now?," meaning why hospice care was being sought at the time it was as opposed to earlier in the trajectory of the terminal disease. Other information sought by HRRV included (a) identifying when hospice was first considered, (b) who initiated the discussion, (c) who made the final decision to seek hospice care, (d) who was involved in the decision making process, (e) how the decision maker became aware of hospice care, (f) if the decision maker received any information when first becoming aware of hospice care, and (g) identifying the perceived benefits of hospice care. As the study proceeded, themes emerged surrounding the barriers to hospice care as well.

Findings of the Study

It appeared that hospice care was first considered one week or less before the patient was admitted to the program (65%). Thirty-two percent of the time, physicians initiated the discussion to seek hospice care, and in 81% of the cases, the decision to seek hospice care was initiated by a health care professional (e.g., physician, nurse, social worker, physician assistant).
When the question "Why now?" was asked of the participant, why the family was contacting hospice at this time, responses related to the fact that a health care professional had suggested they contact hospice. Other responses included being exhausted; physicians noticing the need for additional help for families; physicians suggesting he/she contact hospice because all treatment modalities had been explored and were of no benefit to the patient any longer; patients having less time to live than expected; and in some instances, a family member or a friend suggesting the family contact hospice.

The caregiver most often reported for the patient was a wife (25%), and the perceived decision maker participating in the study most often reported was a daughter (31%). Patients (25%) were involved in the hospice decision making process most often; in 41% of the cases, the patient was involved in the final decision to seek hospice care. In 36% of the cases, patients received information about hospice care when hospice was first discussed with him/her, and the hospice brochure (34.9%) was the item most often shared.

When reviewing the findings from Table 2 and Table 6, a cumulative percentage of the two tables shows that a daughter (43%) was involved in the decision making process most often followed by the patient (35%), a son (28%), a wife (27%), a husband and a physician (13%). Other individuals were involved less frequently. When combining the categories of husband and wife, spouses were involved in the decision making process in 55% of the cases. Another way to interpret the findings would be by sex. In 78% of the cases the decision maker involved was a wife, a daughter, a sister, a mother, a daughter-in-law, or a sister-in-law. If female non-family members are included, the percentage is even greater. Females were clearly involved in the decision making process more often than males.

Seventy-one percent of patients participating in the study were admitted to Hospice of the Red River Valley. When asked if decision makers were aware they could self refer, 25% reported "yes," with relatives (24%) being the most common source of information
about the self referral process. Patient demographics indicate that 44% of the patients were male, 88% of the patients were between the ages of 60 and 103, 49% were married, 33% were widowed, 18% reported being single, and 63% of the patients reported living at home. Cancer was reported as the terminal illness making the patient hospice appropriate in 55% of the cases. Decision makers reported physicians specializing in internal medicine as being the patient's primary physician in 39.6% of the cases.

Benefits reported by participants in the study included the following: (a) support, comfort care; (b) crisis care, the end stage death bed care; (c) education; (d) pain management, symptom control; (e) medication reimbursement; (f) oxygen and equipment (e.g., beds, walkers, commodes, etc.); (g) someone to talk to; (h) bereavement counseling services; (i) access to volunteers.

Barriers reported regarding the decision to seek hospice care included (a) families not being aware of the fact that hospice "went into nursing homes," (b) the criteria for Medicare reimbursement and/or being Medicare appropriate, (c) physicians not being supportive of hospice care, (d) not being aware of the full continuum of services hospice provides, (e) frustration with the lack of hospice care available until end stage death bed care was imminent.

Social workers reported a lack of physician support of hospice care, patients not aware they were dying, or a patient not being willing to "give up hope" or to cease the aggressive treatment modalities as being barriers when seeking hospice care. Social workers also reported that families tend to not understand the Medicare reimbursement process and that families are also not aware of the full range of services provided by hospice.

Finally, and to the point of the study, it appeared that individuals were not aware of the hospice referral process; in fact, many (75%) were not aware of the fact that they could contact hospice without being referred by a physician.
Discussion of the Results With Respect to the Literature Reviewed

Hospice of the Red River Valley is Medicare certified as are 80% of hospice programs in the United States. In 1995 the NHO reported that 60% of all those dying of cancer were receiving hospice services; 55% of the patients in this study reported cancer as the terminal illness making them eligible to receive hospice care. In 1997, HRRV reported that 60% of their patients identified cancer as the terminal illness making them hospice appropriate (M. L. Dahms, personal communication, May 6, 1998). All of the participants in this study reported having a primary care giver or a plan in place to have a primary care giver before being admitted to HRRV, and wives (25%) were most often reported to be the primary care giver for the patient in the study. The National Hospice Organization (1998b) reported that "60% of hospice programs in the United States admit patients without a primary care giver" (p. 2). HRRV is not-for-profit as are 65% of the hospice programs in the United States (National Hospice Organization, 1998b).

Nationally, in 1995, 52% of hospice patients were male and 71% of them were over 65 years of age. In this study, 44% of the patients were male and 89% of the patients in the HRRV study were between the ages of 60 and 103. In 1995, 77% of hospice patients in the United States died at home (National Hospice Organization, 1998b); 55% of hospice patients nationally reported living with a spouse (National Hospice Organization, 1993). Study participants reported that 63% lived at home and 49% were married. Bass et al. (1984) found that 57% of hospice patients died at home and that the shorter the stay in the hospice program, the more apt the patient was to die at home. It appears that patients admitted to HRRV died shortly after being admitted, and patients tended to die at home (M. L. Dahms, personal communication, May 6, 1998).

One in six patients die within six days of admission to a hospice program, according to Christakis and Escarce (1996). In 1995, the National Hospice Organization
(1998b) reported the national average length of stay (ALOS) for all patients admitted to a hospice program to be 61.5 days. M. L. Dahms (personal communication, May 6, 1998) reported that 31% of patients admitted to HRRV had an average length of stay of 1 to 8 days. Dahms also reported that 36% of the patients' ALOS was 8 to 31 days, and 32 days or more was the ALOS for 35% of the cases served in 1998.

Kastenbaum (1998) also concluded that a lack of understanding with regard to the Medicare process was a barrier for those seeking hospice care. He also found physicians' lack of support to be an additional obstacle for families seeking hospice care. Both of these issues were also found to be valid for participants in this study. Many of the participants reported being unclear about the Medicare eligibility criteria as well as the reimbursement process. Social workers participating in the focus groups reported a lack of physician support to be an obstacle for many families when seeking hospice care. It is my experience that Medicare in and of itself can be a confusing concept to understand without the addition of a hospice Medicare dimension to it. I believe that more of an effort needs to be made to assist the public in understanding not only Medicare, but the different components of Medicare, which would include the hospice Medicare benefit. The government could become more pro-active in this area by providing more Medicare in-services or by making Medicare help lines more accessible. Also, it appears that a majority of the participants in this study were confused about the Medicare reimbursement and were also unaware of the fact that they could go on and off of the Medicare benefit.

In a study by Calnan (1983), the findings reported that patients consult with friends rather than family when seeking hospice care. This contradicts the findings of this study as the majority of patients consulted with care givers as well as decision makers when seeking hospice, both of which were family members in the majority of cases. Friends were only consulted in 1% of the cases in the HRRV study and were the reported source of information in 9.3% of the cases. The population in the HRRV study tended to be families
with older family members seeking hospice care. Because of the value placed on extended
family in the region studied, it would be my understanding that the older family member
would seek a family member's perspective on hospice care and assistance in admitting to
hospice care over a friend's in part because of this. Also, often family members will
provide care for older family members until they either become exhausted, or until the
person caring for the ill family member no longer feels capable of caring for the dying
family member. This may be due to limited knowledge, experience, or because it is
becoming too emotionally depleting for him/her to continue to care for the dying family
member. In addition, because of the age of the majority of the patients in the HRRV, many
of his/her peers (friends) may be dead or not able to assist with the decision to seek hospice
care for a variety of reasons (dementia, Alzheimer's, dying his/herself, in a long term care
setting).

It appears that the decision to admit to hospice care was not only a function of the
referral process, but also the families' perceptions of the event and the demands
placed/assigned to them. Participants reported admitting patients to hospice when he/she
could no longer care for the patient alone or when the patient required additional equipment
or care. Jacobson (1986) also believes that the support systems available as well as the
decision maker's perception of the event to be significant indicators when seeking hospice
care.

Gochman and Bonham (1988) also studied the hospice referral process. They
found that the initial discussion to seek hospice care was initiated by a friend, relatives, and
then physicians with the final decision maker being identified as the patient's care giver
(68.3%). When compared to findings of the HRRV study, physicians initiated the initial
discussion to seek hospice care most often (20%), followed by long term care nurses
(14%) and MeritCare social workers (9%). Daughters were the identified decision maker
in 31% of the HRRV cases. The care giver most often reported (wife, 25%) was reported
to have been the final decision maker in 19\% of the cases with the patient reported to have been involved in the final decision in 41\% of the HRRV cases. Again, I would expect that the age of the majority of the patients in the HRRV study to have a direct correlation as to why those persons involved in the direct delivery of health care services were most involved in initiating the hospice referral process for the patient. The older a person is the more tendency he/she would have to be involved with physicians simply because of failing health and the fact that the older one gets, the more likely he/she would be to die.

Gochman and Bonham conducted a second study in 1990. This study showed that 62.58\% of the respondents had heard of hospice prior to their loved one becoming ill with physicians being the most frequent source of information when seeking hospice care; and in 48\% of the cases, the participants received information. Results of the HRRV study suggest that 96\% of the participants had heard of hospice prior to his/her loved one becoming ill, 36\% received information at that time, and the hospice brochure was the source of information most often shared with them (34.9\%). In addition, Bass and Labus (1985) reported that physicians who specialize in either family practice or osteopathic medicine to have referred terminally ill patients to hospice care more often than oncologists did. Decision makers for the HRRV study reported that physicians specializing in internal medicine to be the patient’s primary physician in 39.6\% of the cases, and oncologists were the reported physician in 26.4\% of the cases.

Conclusions and Recommendations

There appears to be a high level of awareness with regard to hospice care reported by the participants in the study as well as many perceived benefits of and barriers to hospice care. Participants seemed unclear about the referral process when seeking hospice care. They also reported confusion regarding Medicare and being Medicare appropriate. Some of the participants did not realize that hospice care was available to residents in long term care facilities and in hospitals. The term "referral" appears to have an inaccurate
meaning for those seeking hospice care. Participants reported not being aware of all of the hospice benefits available to them, and a large majority of the participants were unaware of the fact that they could contact hospice without a physician's directive to do so. Also, for many of the patients and participants, hospice care meant giving up; it meant death.

Education is clearly indicated. Tools could be developed to educate the public with regard to the hospice referral process as well as the full breadth and depth of hospice services available to the terminally ill patient and his/her family. The term "referral" in and of itself tends to increase the confusion with regard to seeking hospice care. Possibly a more neutral term could be discovered that would describe the process more accurately. Participants tend to understand the term "referral" as being equated with the term used by a health care organization to receive health care coverage when seeking health care out of an individual's health care network. Individuals seeking information with regard to hospice care are really on an information gathering mission, and the term "referral" does not appear to describe this process accurately. In addition, when an individual is being admitted to hospice care, the information gathering session has been completed, meaning that this person would no longer be in the "referral process."

An educational tool that could be developed to increase awareness would be a video. One might imagine a person receiving a terminal diagnosis in one breath and in the next breath hearing "hospice" as a suggestion for care and not assimilating all of the information shared. When patients are given a terminal diagnosis, information shared may be lost due to a lack of focus and heightened emotions with regard to the prognosis. If families could have a video available to them to view in their own homes at their convenience, sharing with them the full continuum of hospice services, admissions to hospice care might increase as a result of increased awareness. In addition, if the brochure is provided to patients with a terminal diagnosis, a follow-up contact would be beneficial to the patient to provide an increased understanding of hospice care as the brochure to date
does not address all of the services provided by HRRV. The brochure does not explore Medicare benefits available to patients nor does it fully explain hospice as a benefit to patients in long term care facilities.

There appears to be a wide range of confusion surrounding the Medicare reimbursement process. HRRV could increase understanding of the Medicare process when seeking hospice care by providing in-services for the community and families seeking hospice care. Another avenue to explore would be for hospice to have a Medicare "specialist" on site or to have a contact at the local Medicare office for patients and/or family members to contact for clarification with regard to Medicare benefits for hospice care. Also, HRRV could explain the Medicare process to include a guarantee that there would be no additional cost to the family; they could get more people in earlier.

Hospice also does not have services available for families on a 24 hour basis, not until the patient is in need of 24 hour crisis care (death bed care). Hospice of the Red River Valley does not offer home health care. I believe this is an area HRRV should explore in the future as it seems logical for families to want a full range of services, including home health care. Some of the participants reported having augmented hospice care with home health care and were frustrated with the lack of care available from hospice on a routine basis until the patient required death bed care.

Many of the individuals involved in the hospice decision making process were nuclear family members and many of them were women. Special efforts should be made by HRRV to share information about hospice to women's groups and in those organizations in which women constitute a high percentage of membership. Information shared must be directed to providing the type of information that promotes the full range of hospice benefits, as the qualitative data presented in Chapter IV indicate that families are not aware of the full spectrum of hospice benefits.
The bulletin board currently being used by hospice also implies death bed care. The bulletin board reflects an older gentleman holding his grandson; the message is:

We enter the world surrounded by love, comfort, and care.

Don't we deserve the same when we leave?

If hospice is to be equated with more than death bed care, then the full spectrum of benefits must be brought into awareness for the public. The majority of people know that hospice serves the dying; unfortunately, the association between hospice and death is also strongly tied to the death bed scene. Just as strong is the association between hospice and cancer as the illness making the patient hospice appropriate. Hospice needs to inform the public of the other diseases that have made patients hospice appropriate, such as chronic heart disease, Parkinson's, end stage dementia, gangrene (see Table 17 for a full list).

As a follow-up to this study, research with nurses as well as physicians would be suggested to further understand the hospice referral process as both physicians and nurses were reported as being highly influential in the hospice referral process. Soliciting further information from them would only enhance the findings of this study. The focus groups conducted with social workers contributed to the primary study's findings; continued research in this area would be a benefit to all hospice programs experiencing diminished referrals.

It has been my pleasure to participate in the data gathering process for this study for Hospice of the Red River Valley. As previously stated, my life has been enriched because of this experience.
I ___________________________ consent to participate in an interview study conducted for Hospice of the Red River Valley. The objective of the study is to learn more about how patients are referred to Hospice of the Red River Valley and the perceived benefits to the patient and their family. The study is funded by the Allina Foundation of Minneapolis, MN. Participation in the study involved participating in a telephone interview which will take 20-30 minutes. The data from this study are confidential. Interview responses will be grouped and presented in categories. Benefits to participants include the opportunity to communicate about the hospice selection process with a professional researcher and to share experiences and perceptions. Participants may withdraw from participation at any time and their data will be destroyed if they do withdraw.

Witness: _______________________________

Date: ____________________________
APPENDIX B
HOSPICE OF THE RED RIVER VALLEY
REFERRAL PROCESS INTERVIEW FORMAT

PATIENT NAME: ___________________________________________
CARE GIVER: ______________________________________________
DECISION MAKER: _________________________________________

1. WHO BEGAN THE DISCUSSION? ____________________________
   a. Care giver
   b. Patient
   c. Non-household care giver
   d. Other household member
   e. Health care professional
   f. Non-household member
   g. Non-household non-relative

2. WHEN WAS HOSPICE FIRST CONSIDERED? _________________
   WHO BEGAN THE DISCUSSION? _____________________________
   WAS ANYONE ELSE INVOLVED IN THE DISCUSSION? ________
   _______________________________________________________
   WHO WILL BE INVOLVED IN THE FINAL DECISION? __________
   _______________________________________________________

ADDITIONAL COMMENTS:
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
3. HAD YOU EVER HEARD OF HOSPICE CARE PRIOR TO THE PATIENT BECOMING ILL? YES _____ NO _____

WHEN WAS THE FIRST TIME YOU DID HEAR OF HOSPICE? ________________

ILLNESS: __________________________________________________________

4. DID YOU OR THE PATIENT RECEIVE ANY INFORMATION ABOUT HOSPICE CARE DURING THE PATIENT'S ILLNESS? YES _____ NO _____

WHERE DID YOU RECEIVE THE INFORMATION FROM?

a. Hospice
b. Physician
c. Relative
d. Friend
e. Written print (newspaper/brochure)
f. Clergy
g. Hospital literature
h. Radio/television/billboard
i. Other health care professional

5. WAS HOSPICE CONSIDERED/USED? YES _____ NO _____

DATE OF ADMISSION: ________________

6. WERE YOU AWARE OF THE FACT THAT YOU COULD SELF REFER?

YES _____ NO _____

DISCUSSION: ________________________________________________________
7. WAS THE PATIENT INVOLVED IN A CLINICAL TRIAL?

YES _____  NO _____

DO YOU HAVE ANY QUESTIONS FOR THE INTERVIEWER? ______________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

PERCEIVED BENEFITS: ________________________________________________

PATIENT DEMOGRAPHICS

PATIENT NAME: _________________________________ SEX: M ____  F ____

DOB: ______________

PHYSICIAN: ________________________________

ILLNESS: ________________________________ ONSET: ________________

MARITAL STATUS: M ____  S ____  W ____

LIVING ARRANGEMENTS: _____________________________________________

PERCEIVED DECISION MAKER: ________________________________

BEST TIME TO CALL: _____________________________________________

CALLED: ________________  COMPLETED: ________________
APPENDIX C

MSW FOCUS GROUP GUIDE

1. Approximately how many individuals have you worked with in the past 12 months who have considered hospice care?

2. What do you see as the major benefits of hospice care to the patient and family?

3. What factors had led hospice appropriate patients away from hospice care?

4. Do you think there are more patients who should consider hospice care?

5. What factors tend to delay the decision to begin hospice care?

6. Are there any other things that can help us understand the decision making process of selecting hospice care? Please describe.
III. 1. Office locations for Hospice of the Red River Valley (HRRV).

REFERENCES
REFERENCES


