



The impact of learning on decision making by family members for hospice care
by Betty Marie Neff

A thesis submitted in partial fulfillment of the requirements for the degree of Doctor of Education
Montana State University

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Abstract:

What factors in an individual's life experiences and the learning that attends the experiences most affect the decision making ability of hospice caregivers? To answer this question, eight hospice caregivers were interviewed. The interviews were open-ended and loosely structured around 12 topic areas: hospice care, good and bad points, preference, family, knowledge, beliefs, needs, others, decisions, blocks, life history, and learning. When the interviews were compiled and analyzed, the factors that were perceived to influence most decision making by hospice caregivers were their childhood responsibilities, examples of models (especially parents), life experiences, weighing the pros and cons, marriage, common sense, praying about it, considering options, prior caregiving, talking to others, and the Golden Rule. Other patterns which emerged were the major reasons why the families chose to use hospice care: home environment, relief from pain, needed help, best for well-being of loved one, necessity, convenience, and caregiver disability. A final pattern which described the major blocks to decision making by the caregivers included emotional upsets, fear of losing loved one, having no choice, frustrations, tendency to put off decision making, lack of spousal support, and lack of education. Generally, the study describes the relationship between informal and formal learning and the decision making ability of hospice caregivers.

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Betty Marie Neff

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of the requirements for the degree

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APPROVAL

of a thesis submitted by

Betty Marie Neff

This thesis has been read by each member of the graduate committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

4/20/95
Date

Robert A. Fellows
Chairperson, Graduate Committee

Approved for the Major Department

4/20/95
Date

Joanne M. All
Head, Major Department

Approved for the College of Graduate Studies

5/7/95
Date

R. L. Brown
Graduate Dean

Pointe-Bond
COTTON

Cro

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Signature Betty M. Neff
Date April 12, 1995

This study is lovingly dedicated to the memory of my daughter, Doris Ann, and to the memory of my son, Bill, Jr. I learned a great deal about living, loving, and dying from them.

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ABSTRACT

What factors in an individual's life experiences and the learning that attends the experiences most affect the decision making ability of hospice caregivers? To answer this question, eight hospice caregivers were interviewed. The interviews were open-ended and loosely structured around 12 topic areas: hospice care, good and bad points, preference, family, knowledge, beliefs, needs, others, decisions, blocks, life history, and learning. When the interviews were compiled and analyzed, the factors that were perceived to influence most decision making by hospice caregivers were their childhood responsibilities, examples of models (especially parents), life experiences, weighing the pros and cons, marriage, common sense, praying about it, considering options, prior caregiving, talking to others, and the Golden Rule. Other patterns which emerged were the major reasons why the families chose to use hospice care: home environment, relief from pain, needed help, best for well-being of loved one, necessity, convenience, and caregiver disability. A final pattern which described the major blocks to decision making by the caregivers included emotional upsets, fear of losing loved one, having no choice, frustrations, tendency to put off decision making, lack of spousal support, and lack of education. Generally, the study describes the relationship between informal and formal learning and the decision making ability of hospice caregivers.

CHAPTER 1

INTRODUCTION

The history of hospice in England has been well established, having evolved slowly across a century of tested experience. The women of a Catholic order, the Sisters of Charity, originated the idea of hospices for the dying in Ireland where in the middle of the nineteenth century they often found terminally ill people living and dying alone. More often, they found them in rural homes where a dozen persons were living in a two room hut with the family lacking the space, time, energy, and/or skill to care for them properly. First at Dublin and then elsewhere these Irish nuns provided clean places where dying persons could be brought for care. From Ireland, this work of the Sisters of Charity expanded to England, and as the program grew in insight and numbers of persons served its influence spread to Asia, Africa, and to Australia--but without any impact on the United States until the early 1970s (Rossman, 1979).

The hospice movement in England dates from legislation in the 1960s which made money available for such programs from the national health funds, although other agencies such as the Marie Curie Foundation, which was concerned

with the care of cancer patients, also played a role. With funds available from these sources for research and experimentation and with experienced staff who were able to develop theory and procedures on the basis of careful evaluation of successful work, the hospices of England were able to create a radically different environment for the terminally ill. One of the primary driving forces and a pioneer in the establishment of the first hospices in England was Dr. Cicely Saunders (Rossman, 1979).

St. Christopher's Hospice, located in a London suburb, opened in 1967 and two years later the beginning of a home care program was initiated. When visitors asked how St. Christopher's began, they were told the story of the young Pole who was dying of cancer in a London hospital. "There ought to be a better way to take care of people in your condition," a nurse said to him one day. When that cancer patient died he left his savings of over \$1,000.00 to begin a fund to start a hospice for the terminally ill. He had said to that nurse, "I will be your window in such a building." A staff member of St. Christopher's added, "With that as a start, we had no choice but to go ahead and create a place where patients could be surrounded with a more pleasant life" (Rossman, 1979).

St. Christopher's was a new kind of place and strikingly different from a hospital environment. Although it was located in London, it was situated away from the

noise and rush of traffic and had gardens with trees. The place was light and airy, which created an atmosphere of sharing and community between patients and the staff. The windows reached almost to the floor, so that a patient in bed could see across the gardens and into a busy nearby street. Thus, the patient was not cut off from everyday life, but was able to see the normal activities happening every day. The staff found that to put a patient in a window bed was one of the best cures for depression, along with providing a garden so that patients could be taken into the sunshine (Rossman, 1979).

The furniture in this facility had none of the metal, antiseptic quality that people had come to associate with hospitals. The patients at St. Christopher's who were not in wheelchairs were in low, simple beds which were as mobile as wheelchairs. The hospice beds had a canvas sling which enabled the patient to sit up with semi-reclining support, and each patient was supplied with five huge pillows. Some of the "dying persons" actively involved themselves in a wide variety of activities, such as drama, films, and family celebrations. A different set of rules were in force here and every effort was made to help patients continue with the lifestyle to which they were accustomed. Not only was smoking allowed, for example, but patients who enjoyed drinking were given their preferred drink (Rossman, 1979).

Control of pain was a priority in these hospices, and doctors ordered medication to be administered to patients before the pain began. This procedure eliminated the stress and worry patients endured due to the fear of intense pain and allowed them to interact with their families and friends in a more normal way. Keeping patients pain-free was accomplished in most cases with the help and supervision of the attending physician (Rossman, 1979). These hospices operated under the assumption that addiction to drugs was not an important factor to be considered when a person was in great pain and was at the end of life. What they did consider important was that dying persons were able to have a pain-free and comfortable ending for their lives.

The origins of hospice care in the United States date back to the early 1970s. At this time, Dr. Cicely Saunders from Great Britain gave a lecture at Yale University in Connecticut to an audience that was composed mainly of physicians, nurses, and community representatives on the care of patients for whom cure was no longer possible (Crystal, 1985).

Dr. Saunders' lecture sparked an interest in hospice care in Connecticut by describing how people could die painlessly, peacefully, and with dignity. The Connecticut Hospice was founded in 1974, funded by the National Cancer Institute (NCI), as a demonstration project. Five other

demonstration hospice programs with facilities for inpatient care were begun later (Chase, 1986; Crystal, 1985; Holden, 1976; Saunders, 1973).

These NCI-funded hospice programs served to encourage the formation of other hospice programs of all sizes and types in many communities of the United States. At this time, there were no formal guidelines or financial reimbursements for hospice care, but people generally felt the need for more appropriate options for dying persons and formed hospices according to their resources. By 1983, there were 516 hospice programs in the United States, and by 1989 this number had grown to 1700 programs (National Hospice Organization [NHO], 1990).

In 1977, less than 100 hospice programs formed the National Hospice Organization (NHO). The first annual meeting of the NHO was held November 1978 in Washington, D.C. in order to bring the need for hospice care to the attention of the federal government and the legislators in Congress. The first full-time director was appointed by NHO in July 1980, and the headquarters was established in Washington, D.C. (NHO, 1990).

The movement spread to the Western states, and the Columbus Hospital Hospice program began in Great Falls, Montana, in 1979. This was the first hospital-based hospice in Montana and was one of the charter members of the Montana Hospice Organization. It was licensed in the

mid-1980s by the State of Montana Department of Health and Environmental Sciences. Originally part of the Home Health Care Department of Columbus Hospital, the hospice was reorganized and renamed in 1991 to Peace Hospice of Montana and now works in cooperation with the Montana Deaconess Medical Center in providing services to the area (Peace Hospice of Montana, 1991).

Definitions of Hospice

In 1982 the Montana Hospice Exchange Council defined "hospice" or "hospice care program" as

a coordinated program of home and inpatient health care which considers the terminally ill patient and family as a unit, and which consists of a medically directed, interdisciplinary team of professionals and volunteers acting under a defined hospice administration. The program provides and/or coordinates palliative and supportive care to meet the special needs arising out of physical, psychological, social, and economic stresses which are experienced during the final stages of illness and dying. Formal bereavement services are an essential component of hospice programs. (Peace Hospice of Montana, 1991, p. 5)

Another definition of hospice, as put forth by the Subcommittee on Health and the Environment in 1976, states:

Hospice is a program which provides palliative and supportive care for terminally ill patients and their families, either directly or on a consulting basis with the patient's physician or another community agency such as a Visiting Nurse Association. Originally a medieval name for a way station for pilgrims and travelers where they could be replenished, refreshed, and cared for; used here for an organized program of care for people going through life's last station. The

whole family is considered the unit of care, and care extends through the mourning process. Emphasis is placed on symptom control and preparation for and support before and after death, full-scope health services being provided for by an organized interdisciplinary team available on a 24 hour-a-day, 7 day-a-week basis. (NHO, 1990, p. 2)

The Subcommittee on Health and the Environment also stated certain hospice goals as follows:

1. Keep patient at home as long as possible.
2. Supplement, not duplicate, existing services.
3. Educate health professionals, lay people.
4. Support family as unit of care.
5. Help patient to live as fully as possible.
6. Keep costs down. (NHO, 1990, p. 4)

Hospice Philosophy

The philosophy of Peace Hospice of Montana (1991) is stated as follows:

Hospice provides support and coordinates care for persons facing a life threatening illness and shortened life expectancy so that they might live as fully and comfortably as possible. Hospice recognizes dying as a normal process, whether or not resulting from disease. Hospice neither hastens nor postpones death.

The quality of one's life is not determined by the quantity of time remaining for an individual and his family. Hope is a powerful life force which everyone has a right to maintain. With appropriate care and the promotion of a caring community sensitive to their needs, patients and families may feel free to attain a degree of mental and spiritual preparation for death that is satisfactory to them. With these statements in mind, we believe Hospice affirms life. (p. 5)

Peace Hospice of Montana provides the hospice staff and volunteers who provide care to patients primarily in

their homes. It is staffed by a director, who is a registered nurse; an attending physician, an oncologist; a patient care manager, a registered nurse; several registered nurses, who are hospice nurses; a social worker; a pastor/spiritual counselor; and a certified home health aide (Peace Hospice of Montana, 1991).

The program is accredited by the Joint Commission on Accreditation of the Health Care Organizations and is certified by Medicare to offer hospice benefits to Medicare and Medicaid beneficiaries, as well as to those individuals who have private insurance coverage. Arrangements can be made for the client's insurance to help with the financial considerations if the client is insured and under the age to be eligible for Medicare. Otherwise, the family will need to search out help with funding from Medicaid or to assume the responsibility for the expenses themselves (Bete, 1992, 1993; Peace Hospice of Montana, 1991).

Hospice care for terminal patients has fulfilled a vital service for residents of the state of Montana. The criteria for receiving hospice care include a form signed by the patient's physician stating that in the physician's professional opinion the patient has 6 months or less to live (Peace Hospice of Montana, 1991).

Several important questions that the family need to consider soon after learning of the terminal illness include (a) will the terminally ill person accept hospice

care, (b) is there someone in the family who is able and willing to assume the role of the 24-hour caregiver, (c) is the designated caregiver willing to work with hospice to learn how to care for the ill person, (d) is the caregiver prepared through informal life experiences or by formal learning experiences to make the difficult decisions that will be required, and (e) who might help make the difficult decisions?

Some of the decisions involve deciding whether to use the services of home care aides and personal care attendants, the reevaluation of pain medications and other medications as the condition of the client changes, and the probable need for special equipment such as a hospital bed, a wheelchair, walker, and other equipment that maintains mobility and comfort for the client. Hospice stresses care of the client in the home, but in the event that palliative care is needed during the illness, arrangements are made by the registered nurse for the client to go to the hospital until the emergency nature of the situation is resolved; then the client is returned to his home for care.

Assuring the client and the family that a member of the hospice staff is on call and available 24 hours a day, 7 days a week to help the client and the family meet their special needs is part of the team approach of Peace Hospice of Montana.

In addition, if the 24-hour caregiver or other family members need a respite from the continuous care of the client, arrangements are made to place the client in a long-term care facility for a few days or a week or have a respite person stay with the patient to relieve the caregiver for time away from home. Burnout by the continuous caregiver is always a factor to be watched for and prevented by utilizing other caregivers, whether it is family members, hired help, or a health care facility (Peace Hospice of Montana, 1991).

When utilizing hospice care, a number of benefits become readily available. The decision maker can ask for help from anyone on the hospice team when making difficult decisions. The registered nurse, who is available 24 hours a day, can contact the physician for new orders or can make independent decisions regarding pain control medication or other needs. The nurse visits as often as the family needs and orders special equipment for use and convenience in the home. Home health aides, who are adept at providing personal patient care and comfort, are available to help with baths, ambulation, and any other care that is needed. The housekeepers provide cooking, cleaning, and laundry services several times a week. Also available are volunteers, an important part of the hospice team, who do shopping and errands for the caregiver. Counseling for the patient or for the caregiver is another important benefit,

as the need to share feelings with someone else is often profound (Ahronheim, 1992).

In summary, hospice care includes the following services: skilled nursing care, personal care, respite care, medical social services, dietary counseling, spiritual counseling, physical therapy, speech therapy, volunteer services, case management for coordination of services, and bereavement follow-up care (Peace Hospice of Montana, 1991, p. 7).

Problem Statement

Although a number of studies have been conducted regarding health care professionals' decision making skills, few studies have been found regarding learning and its impact on decision making by family members of loved ones who received hospice care.

The problem lies with the fact that some individuals are able to make decisions during great emotional stress while others are not (Rubin, 1985). What factors influence this ability and can it be taught to others? The importance of prior informal learning should not be overlooked as this may very well be a basis for good decision making (Tough, 1971).

This study examined various aspects of learning that have helped with decision making. The process of making decisions is often difficult when one is leading a stable

life; however, when situations arise that are fraught with high emotions, such as great sorrow, these can cause real blockages for making decisions (Rubin, 1985).

In view of the evidence supporting demographics which point toward an increased geriatric population by the year 2000 (National Association for Home Care, 1995), and as more and more individuals are expressing a desire to remain in their homes during the last days of their lives, this study examined some of the problems associated with decision making when individuals have experienced extreme emotional stress. It also examined how life experiences and the learning process affect their decision making ability.

Research Questions

1. In what way does learning affect decision making?
2. How do life experiences affect decision making for hospice?
3. What were some of the blockages experienced when trying to make decisions in hospice situations?
4. Who made the difficult decisions and were they prepared to do so? If so, by what means?

Definitions

Definitions of terminology used in this study are as follows:

- Learning--acquiring knowledge or skill by study, instruction, or experience.
- Hospice--a program, begun in England in 1967, that eases the last days of terminally-ill patients and assures a natural death in as homelike surroundings as possible.
- Terminal--(of a disease) considered likely to be fatal.
- Decision--a making up of one's mind.
- Decision theory--a body of concepts dealing with making rational choices and evaluating risks.
- Depression--a state of low mental vitality, dejection.
- Hopelessness--without hope, affording no reason for hope.
- Helplessness--unable to tend one's own needs, unable to act at will.
- Anxiety--intense dread, apprehension, nagging worry, or an instance of this.
- Resentment--to take strong exception to what is thought to be unjust, interfering, insulting, or critical.
- Judgment--the ability to weigh matters prudently, the process of assessing.
- Stress--a state in which a strong demand is made on the nervous system.
- Denial--an unconscious defense mechanism in which emotional conflict and anxiety are avoided by refusing to acknowledge thoughts, feelings, or facts that are consciously intolerable.

Delimitations

This study is delimited to the geographical area served by one specific hospice, Peace Hospice of Montana. The people who were interviewed were residents of the city of Great Falls, Montana, which has a total population of 69,000. The main occupations of individuals in this area include farming, cattle raising, small business, service industries, and active, as well as retired, military personnel.

Hospice patients, themselves, were not interviewed. The pain and discomfort that many hospice patients endure could have made such interviews difficult. Instead, the hospice patient's family and significant others were interviewed. These individuals, while they were closely involved in the situation, were not the direct object of the terminal illness, and it was found that these individuals were able to examine and report more clearly on the emotional issues and the decision making techniques involved during this stressful time.

CHAPTER 2

REVIEW OF THE LITERATURE

Previous studies regarding learning and decision making by family members during extreme emotional upheaval are limited in number. However, one such study, "An Ethnography of Hospice Home Care" by Marguerite Stuhler-Schlag, Ed.D. (1985), was conducted at Rutgers University and did include family members. This research explored hospice services delivery by a New Jersey home health agency in order to identify the process of decision making required by professional nurses and families participating in the delivery of terminal care in the home setting.

Analysis of paired-comparison interviews for both the nurses and families identified four areas that required continuous decision making: eligibility, symptom control, methods of intervention, and rehospitalization. Full descriptions of the conditions that affected the decision making process of the participants in hospice home care were discussed. Although there was general agreement about the goal of a home death, the expectations about care were not congruent at all phases of the dying process (Stuhler-Schlag, 1985).

During the 18 months of field work, data were collected on the nurses, patients, and families participating in hospice home care. Detailed analysis was done on the interviews and observations of 12 nurses and 7 hospice families (Stuhler-Schlag, 1985).

Instead of an interdisciplinary team approach to care in the hospice concept, the nurses and family in this study formed a partnership directed at the goal of a home death for the patient. This partnership produced a cultural system whereby it was believed that shared values, beliefs, and expectations preserved the quality of the patient's life throughout the dying process (Stuhler-Schlag, 1985).

In order to work with each new patient and family, the nurses approached the family to determine the terminally ill person's eligibility for the hospice program. The nurses held the common belief that the family should communicate in some way an attitude of trust, honesty, concern for the patient, commitment to the hospice goals, and a competency to provide the care. When these requirements were met, the nurses felt they could work with the family as a partnership (Stuhler-Schlag, 1985).

The family was also asked to evaluate the nurses as potential partners in the patient's care. The family described the qualities of a hospice nurse as truthfulness, dependability, nonjudgmental, and an open and accepting attitude of the family situation. The resulting

partnerships were tailored to meet the special needs of each family, and in order for the partnership to work at its best the nurses had to move from a position of an outsider into the family system. This involved assessing the patient's needs and determining if the caregiver was both emotionally and physically able to carry out the plan of care. The nurses wanted the family to understand the patient's problem and why certain things had to be done (Stuhler-Schlag, 1985).

The partnership between the nurses and the family helped to instill confidence in the caregiver's ability to provide care. The nurses taught the caregivers how to interpret changes in the patient's condition and how to help the family reorganize its daily activities to meet the new demands of patient care in the home. Other benefits for the caregiver that developed from this relationship were feelings of ease in asking questions and making independent decisions about the care when the nurse was viewed as an equal partner in the patient's care (Stuhler-Schlag, 1985).

Demystification of death was another aspect on which the nurses focused. Family members often had an unreal idea of how death occurred and the symptoms which accompanied this event. None of the families had experienced a home death, although most had some experience with death. Many people in today's society view death as a

mystery, according to Herman Feifel (1977). This is due in part to the increase in fragmented families and in the impersonal technology of our hospitals where most people die. Movies and television programs that portray death as agonizing and horrible events add to this misconception (p. 5).

Hospice families, in this regard, are no different than other families in America insofar as they have visualized what a home death might be. After a time in which to determine the stability of the patient and the family and in order to allay some of these fears, the nurse gradually introduced some of the facts regarding signs and symptoms of impending death. She also encouraged them to share their views of death and what they thought death would be like. By demystifying death for the patients and families, the nurses were able to help the families gain control over the death event and add support to the families in adapting to a home death (Stuhler-Schlag, 1985).

The nurses' activities aimed at demystifying death for the families in Stuhler-Schlag's study were similar to the events listed by hospice users in the study by Gold (1983). Caregivers in a hospice home care program were asked to identify factors which enabled them to cope with the death event without undue trauma. They listed the following factors:

1. Adequate forewarning and preparation.
2. Explanation of physical manifestations of approaching death.
3. Opportunities to comfort or ease the patient's distress.
4. Opportunity to communicate with the patient.
5. Opportunity to witness the death, if desired.
6. Time alone with the body, if desired.

(Gold, 1983, p. 137)

Coping with the death event, the feeling of being overwhelmed and the feeling of powerlessness were pervasive throughout the hospice families. Amazingly, the sense of powerlessness did not arise from the fact that the patient would die but that the families did not know when the death would occur. To help overcome the feeling of powerlessness, the hospice nurses encouraged family decision making in the patient's care and reminded them that what they were doing was worthwhile and meaningful (Stuhler-Schlag, 1985).

In summary, this study emphasized the following learning aspects for the hospice home caregiver: self-confidence building, methods of decision making by family members, personal examination of one's own views of death, the many signs and symptoms of impending death, personal care of the patient, how to avoid "burnout," and how to provide a peaceful and dignified death for the patient.

A second study in which the researcher addresses the issue of the protection of patients by ensuring that they receive assistance in asserting their rights as autonomous decision makers is by Lois Webster Winston (1989) in which she affirmed the importance of the role of ethics

committees in protecting patients. This study identified the organizational characteristics associated with the presence of an ethics committee in 108 short-term general hospitals in Southern California. Ten variables were used to operationalize the constructs of structure, strategy, technology, and processes. The most important explanatory variables were size and hospice affiliation. The author of this study suggested that future research is needed to more fully understand the role of ethics committees in the decision making process, particularly when there is a conflict of value systems.

"Perceptions of Dying: A Study of Hospice Volunteers," written by Rachel Crystal (1985), investigated the change in perception about life and death which occurred as volunteers attended the hospice training sessions and worked with terminally ill patients and their families. Three interviews apiece were conducted with six volunteers. The interviews were open-ended and loosely structured around ten topic areas: death, dying, mourning, relationships, living, time, decision making, communication, hospice, volunteering, and role. Conclusions reached showed that the area of greatest change was in the area of communication. This author explored therapeutic intervention with the dying by other than professionals in the field. This related to making use of the wisdom of individuals in a community as much as the technical

expertise. She concluded, "I found the same wisdom, the combining of heart and mind, within the literature, but I have tried to show that this isn't confined solely to professionals in the health and mental health fields" (Crystal, 1985, p. 166).

In a study done by Leloudis and Pole (1985) regarding how primary caregivers make decisions, structured interviews were used with patients and primary caregivers to describe and compare the factors they considered important when deciding to use hospice care. Participating in the study were 9 patients and 12 primary caregivers. The patients' average age was 61 and all but one patient had cancer. Six of the caregivers were women and six were men; their average age was 59 years.

Help for the primary caregiver with patient care by professionals, especially nurses, was important as well as 24-hour service 7 days a week. Most had no one else in the home to assist them. Much concern about the effect caregiving would have on the caregiver was expressed by both the patient and the caregiver.

Emotional as well as physical support was also important. Limited finances, since hospice was less expensive than hospital or nursing home care, was a major consideration. Life-prolonging measures not used by hospice and not wanted by the patient in most cases was a factor.

In this study, home interviews were done with both the patient and the caregiver. Open-ended questions (12) were used regarding how patients and primary caregivers perceived hospice care and how the decision to use hospice services was made (Leloudis & Pole, 1985).

In summary, all participants reported that being at home was of primary importance, and all except one identified this as influential in making the decision to use hospice. When asked what was important about being at home, 6 of the 9 patients said they simply wanted to be there, and 7 primary caregivers said they simply wanted the patient there. More time with loved ones was a major factor, and 9 participants said it was important for the patient to be independent and to be able to control surrounding events (Leloudis & Pole, 1985, p. 34).

Daleo (1986), reported an interesting study that was done by The National Institute of Occupational Safety and Health (NIOSH). Researchers studied 22,000 workers of 130 different occupations. The investigation was designed to study the types of jobs that lead to stress-related illness such as heart disease, high blood pressure, ulcers, and nervous disorders. The results demonstrated that one of the most stressful occupations is the health care worker because these workers had a "great deal of responsibility for the welfare of their patients without the authority to have complete control over that welfare" (p. 33). In

contrast, it was found that "decision makers" such as doctors, lawyers, and executives were reported healthier. This was not because their jobs were stress free, but because they had a large degree of control over daily decisions (Daleo, 1986).

For those individuals who did not have a large degree of control over decisions in their lives, losses experienced at a time like this were control, identity, and relationships. The diagnosis of a life threatening illness catapults the patient and the family into an irreversibly altered reality. Family members often "comment that the date of diagnosis is as powerful an anniversary as the date of actual death" (Sourkes, 1987, p. 22).

It was further stated that:

The family caregiver must engage in an ongoing honest appraisal of his/her capacity for repeated cycles of detachment and loss with an awareness of and respect for one's limitations. It is only within the context of one's own psychic reality that the ability to take emotional risks, to experience and witness deep feelings, has meaning. Emotional risk taking without recognition of these limits leads to an intensity that burns itself out. (Sourkes, 1987, p. 24)

Elements of Learning

Practical learning is preferred by adults as indicated by Tough (1971), Knowles (1980), Houle (1972), and Smith (1982). The reasons adults engage in learning are many and include the following:

To satisfy curiosity or puzzlement or to answer a question, to enjoy the content itself, to enjoy practicing a new skill, for the pleasure of learning, to complete unfinished learning, to associate with other learners, and to benefit from a change in routine. (Tough, 1971, p. 28).

In the case of this study, the most important reason for learning something new most likely would be to answer a question such as, "What do I do now?" The importance of prior informal learning for a caregiver for hospice care should not be overlooked as this may very well be a basis for good decision making (Tough, 1971).

How do adults learn when under stress? Although human beings have a natural potentiality for learning, it is only when a person has a goal one wishes to achieve and that one sees as relevant to oneself that one can learn rapidly. However, if the learning involves a change in self-organization--in the perception of oneself--it becomes threatening and tends to be resisted (Rogers, 1969).

In addition, according to Rogers (1969), "Those learnings which are threatening to the self are more easily perceived and assimilated when external threats are at a minimum" (p. 157). The individual who has just been informed that a family member is dying has come face to face with a learning that is not only threatening to the self, but one that is also an external threat. This often results in a sense of fear that can be paralyzing; and in

this emotional state, decisions are impossible to make and are usually deferred to others.

However, when the threat to self is low, experience can be perceived in a differentiated fashion and learning can proceed (Rogers, 1969, p. 158; Conti, 1977, p. 40). If a person has already had experiences with death and dying prior to the present situation, he may react differently now. And, having already had this experience, the person may transfer this past learning experience to the present (Rogers, 1969, p. 158).

One of the principal factors that influence the learning of new material, according to Ausubel (1982), is

an individual's organization, stability, and clarity of knowledge in a particular subject matter field at any given time. If the existing cognitive structure is clear, stable, and suitably organized, it facilitates the learning and retention of new subject matter. If it is unstable, ambiguous, disorganized, or chaotically organized, it inhibits learning and retention.
(p. 5)

These same factors influencing learning are also suggested by Barer-Stein and Draper (1988, p. 76).

White (1988) has similar views as he stated that learning is mightily affected by knowledge, attitudes, and abilities. According to White, "Learning is not the simple absorption of knowledge but the construction of meaning through the individual's relating things seen and heard to things already known. Learning is active, not passive"
(p. 18).

Making a decision involves the steps of setting out options, withholding action, and evaluating likely costs and rewards. Individuals who make decisions apply this strategy frequently when they ask, "Is there another or better way to do this? Which is the better one? How long will they take?" Deciding between options involves making a judgment about the worth of rewards and the cost of penalties, estimating the chance for success, and selecting the option to use (White, 1988).

Further, White (1988) reported that one's attitude toward a concept is the person's collection of beliefs about it and episodes associated with it, especially those that are linked with emotional reactions. The stimulation of these reactions affects decisions to engage in behavior, such as choosing to use hospice care or deciding to place the loved one in a nursing home. Judgments of the likelihood of success and of the relative weights of rewards and penalties draw on experience. Prior experience is crucial in deciding whether to act or not. There is no problem in familiar situations, as there is a group of relevant episodes in memory, so when one comes to a new situation, one can base judgment on experience with earlier situations and experiences. However, when faced with an unfamiliar situation, such as hospice care often is, one may seek parallels between it and familiar ones. If

parallels are found, fine; but if not, that is the time that more outside help and knowledge is needed (p. 100).

This belief in one's ability to draw on parallels between familiar and unfamiliar situations is also expressed by Malcolm Knowles' (1980) philosophy, in which he asserts "a concern for the development of persons, a deep conviction as to the worth of every individual, and faith that people will make the right decisions for themselves if given the necessary information and support" (p. 67).

What capacities are necessary for a person to competently decide about hospice care? Two are primary, according to Buchanan and Brock (1989, p. 18). The capacity for understanding and communication and the capacity for reasoning and deliberation are needed. Although these capacities are not distinct in themselves, deficiencies in any of them lead to less decision making competence. A third important element of competence is that the individual must have a conception of the good or a set of values that are being utilized.

As Linskie (1983) stated,

the base process in learning is not a series of unrelated hook-ups but the discovery of the structured organized wholeness of the environment. This leads to quite a different pattern of learning--not drill and memorization, but understanding and generalization. The more generalizations we develop, the easier it becomes to develop larger categories. Much human problem solving is not done by logic, but by a

reorganization of the problem material itself.
(p. 128)

Elements of Decision Making

According to Wheeler and Janis (1980), two central ideas of decision theory must be kept in mind whenever a vital decision is to be made.

1. In order to make a sound decision, it is necessary to make the best estimates of the probabilities of the expected consequences.
2. A sound decision requires taking into consideration the importance of each of the anticipated favorable and unfavorable consequences--their expected usefulness from one's own standpoint. (p. 253)

Wheeler and Janis (1980) maintained that the use of these two ideas leads to a choice that is favorable. In addition, one will be less likely to overlook serious drawbacks or to give undue weight to other considerations that are really not essential or that are unlikely to come to pass. One will be in a better position to make a choice that meets the main objectives and gives the best chance of overall gains.

Using scenarios is one way to deal with the uncertainty of the future. The scenario, a sketch of what might happen in the future if a particular choice is made, may cover only a small aspect of the future or may include several scenarios. As a result of constructing scenarios, the individual may become aware of some potential risks and

some potential gains that he/she had not thought of before (Wheeler & Janis, 1980).

It is impossible to make sufficiently good estimates of the probabilities for the scenarios, as uncertainties make it impossible to use the scenarios to make specific predictions about the consequences of alternatives; however, scenarios make it much easier to think about the possibilities of the future instead of the probabilities. Scenarios can help make plans to avoid pitfalls and to take advantage of the opportunities that may occur (Wheeler & Janis, 1980, p. 81).

Other elements of decision making include the five stages of effective decision making in which each stage deals with different issues that are important to the eventual decision. Each stage also has its own method and its pitfalls. Further, if any of the stages is omitted or done poorly, the overall process is flawed and chances of failure are greater. The five stages are accepting the challenge, searching for alternatives, evaluating alternatives, becoming committed, and adhering to the decision. Several countermeasures which can be utilized for overcoming setbacks and salvaging decisions that may turn out badly are described by Wheeler and Janis (1980, p. 253).

According to Rubin (1985), a sound decision is a free, unconditional, total and personal commitment to a favored

choice or option. In decision making, the individual holds nothing back, and uses the feelings as well as the logic in becoming committed to the choice made. Further, it means feeling strongly about the choice and caring enough to invest time, energy, thought, talent, and assets toward the successful outcome of the decision. He further proposed that making decisions makes one own more of oneself and in the long run leads to more fulfillment, greater satisfaction with oneself, and more success in life (p. 11).

Full commitment to a single choice is important. If followed, the road of commitment leads to the favored choice. However, if the situation suddenly is altered, a change of mind is certainly in order as long as it has had some thoughtful consideration. When a decision is made, and it is a personal decision, it shows that the person is in charge of his own life. Rubin (1985) stated that the making of decisions enhances a personal feeling of solidity and increased self-confidence. A decision should be made freely, without undue coercion or influence and without fear of reprisal when not complying with others' wishes (Greenwald, 1973; Johnson, 1992; Rubin, 1985).

Making a decision involves dedicating the full self to integrating, unifying, and mobilizing all of one's assets for the chosen choice. This concentration of inner assets has a therapeutic effect and leads to integrated action,

and action then leads to the fulfillment of the goal.

Rubin (1985) maintained that real decisions make a person own more of themselves by working with the process of choice and personal full commitment (p. 13).

Blockages which Rubin (1985) believed hinder good decision-making include hopelessness, depression, severe anxiety, and resignation. Lack of confidence or poor self-esteem, fear of making a bad choice, impaired judgment, and option blindness are several equally destructive attitudes and beliefs (p. 28).

During a time of crisis, which occurs when an individual is contemplating the death of a loved one, coming to terms with the emotional pain and rising above the pain long enough to make decisions is difficult. Intellectually, each person knows that loved ones will die, as all will, but hearing that death is imminent and that time has about run out is almost impossible to believe. This knowledge can only be taken in a little at a time.

Learning and Decision Making

What does learning have to do with problem solving and decision making? Gagne (1962) has suggested that, for one thing, "the solving of a problem is a set of circumstances which must have been preceded by learning." In order to successfully solve the problem of caring for a dying loved one at home, one must have some knowledge of what this

involves and the many helps and options available for help (p. 12).

Gagne (1962) also put forth the proposition that problem solving, regardless of what may have preceded it, is itself a form of learning. For the purposes of this study, the example of an individual who has had the stimulus of learning about a loved one's impending death might respond by trying to learn about as many options as possible, then combine these options with prior life experiences and come up with a decision. Environment, attitude, general health, finances, and a myriad of other aspects would also combine with the problem solving technique and either work for or against the decision maker.

Human learning, said Thorndike (1968), consists of changes in the nature and behavior of human beings, and those situations or experiences which he encounters form a basis of connections. These connections are tendencies to call forth some one particular response or one of a certain few responses. Learning, according to Thorndike (1968), consists in part of changes in the strength of the stimulus-response connections. It is simply an expression of the probability that a certain stimulus will be followed by a certain response. Thus, prior experience in the individual's life regarding how to care for an ill loved one, or any other health care issue, would form connections

in the mind of the caregiver that the individual could put to good use when making a decision later (p. 4).

Another aspect of learning was proposed by Bayles (1970) when he defined learning as a change in and a development of insight rather than strictly a change in behavior. Or, as he said, behavior may change as an outcome of a change in insight.

Bloom (1976) agreed that an individual should increasingly be able to make decisions--with age and experience--where learning is purposeful and systematic, and where learning is exploratory. In the event that the individual has had little or no prior experience with death and dying, the learning might be exploratory to gain all the facts needed to make an appropriate and satisfactory decision.

Darkenwald and Merriam (1982) propose that learning goals often come from needs that are personal, religious, social, cultural, or for escape. The need to be able to make important decisions when confronting a hospice situation would most likely encompass all or most of the needs mentioned above.

Lindeman (1961) advocated the situation approach to learning and wrote that "the best teaching method is one that emerges from situation experiences." (p. 115). These situations which merge from his work, his recreation, and his family life frequently call for adjustments. It is at

this point that education of the adult begins. His approach includes (a) a recognition of the situation, (b) an analysis of the situation, (c) discussion of the problems in light of available information, (d) use of information to formulate solutions, and (e) acting upon a solution. This is, in essence, the basic methodology for good and useful decision making.

Death and Dying Concepts

As Rossman (1979) said, "People do not fear death so much as they fear dying, a process which for many persons--young as well as old--is a slow, painful, and very lonely experience" (p. 23). Dying is not an instant happening, as many suppose. It occurs over days, months, and sometimes even years. Occasionally, violent deaths are instantaneous, but they are in the minority. Therefore, after it has been determined that cure is impossible, this should be a time of renewing relationships with family and friends, so that a meaningful life can be enjoyed to the end. Instead, despite all the latest advances in technology and the millions of dollars this country is pouring into the research and war against cancer, little attention is paid to the plight of the victims once their battle appears to be lost.

For example, Holden (1976) stated that of the 700,000 people who are diagnosed yearly as having cancer, two out

of three die of the malignancy. Thus, terminally ill persons often find themselves feeling isolated, miserable, helpless, and out of control of their life (p. 389).

In many cases, the medical profession's zeal to prolong life has merely succeeded in prolonging death in a cold-blooded, impersonal way. Instead of a person's life coming to a dignified and meaningful ending, it ebbs away in a hospital intensive care ward, hooked into machines, with jabbing needles instead of loving touches. Most people are willing to surrender some freedom in order to be cured of a serious disease, and to save one's life if one can become free and happy again, but when one is terminally ill and ready to die, this prolongation is not a kindness, but a very subtle form of cruelty. Most people want to be in a happier environment, and that often means "home" (Arnold, 1992; Holden, 1976; Rhymes, 1990).

C. S. Lewis (1961) described a satisfying experience with his dying wife: "It is incredible the happiness we had together after all hope was gone. How long, how tranquilly, how nourishingly, we talked together that last night" (p. 61). Such an experience does not mean that all difficulties and suffering are gone when pain that is physical, mental, social, and spiritual is carefully attended to, but it does suggest that there are many alternatives that can be explored that may make life more

bearable and give the dying more dignity and the survivors better memories.

And, as Dobihal (1974) said,

The world is not made perfect for those who are dying nor for those continuing to live. The hospice will not be a perfect environment but we can give patients and families the best care we can devise, and then share our discoveries with others who are serving the dying elsewhere. At least, the hospice can be a place where people care and have time to share. (p. 365)

Death, then, according to Bertman (1991), not only evokes horror, exhaustion, and separation, it can also be an opportunity for existential communion. It can remind us of the preciousness and wonder of life and of the specialness and connectedness we share with one another. Death is the backdrop against which we play out our mortality and enact our humanity (p. 34).

Emotions and Decision Making

Since it is recognized that emotions play such an important part in the process of decision making (Greenwald, 1973; Johnson, 1992; Rubin, 1985), five emotional variables were examined. Denial, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969) are the emotions of grieving that are usually experienced. At first, shock is felt and denial is experienced. The coping mechanism of denial serves the useful purpose by giving one time to mobilize other defenses and maintain

hope. Denial allows an individual to recover from the shock and to go on with life. An individual who is placed in a position of making important decisions regarding the care of a loved one may put off making a final choice while experiencing denial. If a decision is made during denial, it is likely to be faulty, due to the distortion of judgment in the decision maker during this time of emotional upheaval (p. 38).

Anger can cause the decision maker to come to grips with the problem, but often leads later on to blaming of self and blaming of others for the situation at hand. Guilt is often experienced as an offshoot of anger, especially if someone other than the decision maker is placed in charge of caring for the loved one (Kubler-Ross, 1969, p. 50).

Bargaining is employed in various ways. It can be a method used to delay the inevitable outcome of death by promises by the decision maker of improved behavior in the future, by offering God and others promises of helping their fellow man, or by any promise which would forestall death. This emotion, bargaining for the life of a loved one and raising false hopes, can be very detrimental to making good decisions (Kubler-Ross, 1969, p. 82).

Once the outcome appears hopeless and the decision maker recognizes that the death of the loved one is inevitable, the decision maker experiences a sense of

hopelessness, helplessness, and depression. The depth of the depression affects the ability of the decision maker to make rational decisions, perhaps because they may feel that nothing will help any longer. Due to this hopeless feeling, they will often defer decisions to others. Individuals feeling despair frequently feel alone and isolated, and when this feeling occurs it is crucial to make reconnections to other people. The physician can help, as can other family members, and if family members are unavailable, professional counseling or joining a support group can be helpful (Kubler-Ross, 1969, p. 85).

The sense of acceptance, of finally realizing that the death of the loved one is imminent, brings forth a calmness and a sense of clearness of thought to the decision maker. At this time, the decision maker has gradually worked through the earlier stages of grieving and has begun to accept the final outcome. Decisions made when one is in the acceptance stage are usually made more easily and will be more rational. Understanding the options and the alternatives that are available will help deal with these feelings, as will advance planning by the loved one of legal, financial, and social matters. Making decisions that maintain dignity and hope for the loved one is essential (Kubler-Ross, 1969, p. 112).

Accepting Hospice

Determining whether or not to consider using hospice care for a terminally ill loved one will depend on several factors. First, the decision will depend on the wishes of the dying person; second, what the family chooses will depend on whether a family member is willing to become the 24-hour caregiver; and the third factor will depend on the length of time that the loved one has to live. In order to receive hospice care, the physician must make a determination that the dying person has a prognosis of 6 months or less.

Some of the elements of hospice care that people have found important to consider include the support team approach of hospice workers. This team includes a physician, a registered nurse, a certified hospice nurse aide, social worker, pastor, occupational therapy and physical therapy personnel, a counselor, housekeepers and volunteers (Ahronheim, 1992).

When utilizing hospice care, a number of benefits become readily available. The decision maker can ask help from anyone on the hospice team when making difficult decisions. The registered nurse, who is available 24 hours a day, can contact the physician for new orders or can make independent decisions regarding pain control or other

needs. The nurse will visit as often as the family needs her and will order special equipment for use and convenience in the home. The nurse aides, who are adept at providing personal patient care and comfort, are available to help with baths, ambulation, and any other care that might be needed. The housekeepers provide cooking, cleaning, and laundry services several times a week. Also available are respite people who stay with the patient and relieve the caregiver for time away from home. Volunteers are an important part of the hospice team by doing shopping and errands for the caregiver. Counseling for the patient or for the caregiver is another important aspect, as the need to share feelings with someone else is often profound (Ahronheim, 1992).

CHAPTER 3

PROCEDURES

The general design of the study was qualitative. The study examined the strategies by which decisions were made by individuals who have experienced the extreme emotional stress of hospice, and how this process was influenced by prior learning experiences.

An examination was conducted of the behavior of family members during the decision-making process who utilized hospice care within the past 18 months. All the participants in this study experienced the common event of decision-making for a terminal loved one. This study examined human interactions; therefore, the researcher developed 8 case studies which presented an in-depth, synthesized treatment of the collected data.

In citing the work of Cabot and Kahl (1953) on case studies, Seaman & Fellenz (1989) suggested "the analysis of human interaction is much too complex and variable to rely on standards generated through an objective approach" (p. 111). Further, "the study of a number of cases demonstrating varied examples of personal interaction in similar situations produces a better understanding of human behavior" (p. 111).

The term "case study" refers to a description of a real situation that is complex enough for analysis. This approach is process-centered and very well suited to higher cognitive objectives, such as analysis and synthesis of ideas. The genius of the case study is the presentation of conversations and a sufficient history of the individual to establish a social context for the situation and the elimination of value judgments or reasons why events occurred as they did. Case studies allow the reader the freedom to evaluate the information according to their own concepts, values, and wisdom (Seaman & Fellenz, 1989).

Dooley and Skinner (1977), in their case study monograph, state that the case study should analyze the situation not fix it. The researcher must identify specific problems to analyze, using "no blame, no excuses" as a guideline. In other words, the researcher must see clearly what is going on but should not get personally involved in the situation or make judgments as to why individuals responded as they did to the interview questions.

This study utilized the following suggestions put forth by Cameron (1982) regarding the process of analysis:

- a. Took an insider's perspective, developed an overview of situation and people,
- b. Listed basic problems facing various participants and distinguished between symptoms and real issues,
- c. Organized and critiqued the information available,

- d. Acted from the viewpoint of a participant in the situation. (p. 3)

Due to the nature of the topic and the emotional and physical stress that had been experienced by the informants, particular care and sensitivity was used when interviewing the informants. All data were held confidential, and anonymity of informants was maintained throughout the research. Participants were asked to sign a permission form agreeing to the interview before the interview began. No attempt was made to conceal the identity of the researcher or the research study. The researcher was identified as a registered nurse, a licensed teacher of nursing for adults, a certified distance learning instructor (via computer), holder of masters degrees in education and career guidance and counseling, and a graduate student at Montana State University who was doing a study of learning and decision-making in hospice care for a dissertation.

Since very little was found in the literature about the decision-making process of family members using hospice care, a set of interview questions rather than a structured questionnaire was used to gather information. These questions were field-tested by interviewing 5 members of the hospice team at Peace Hospice of Montana which included 2 registered nurses, 1 volunteer, 1 social worker, and 1 hospice operations assistant. Their ideas and suggestions

were incorporated into the interview questions before using them in the study.

The individuals who were interviewed were family members or significant others of individuals who used hospice care during the past 18 months. From a total of 163 bereaved people, 13 women and 12 men were chosen with the help and assistance of Peace Hospice of Montana professionals. These hospice professionals knew the families personally and were experts in their field. The criteria used for choosing the 25 people were their interpersonal skills, their ability to articulate their experiences, their willingness to discuss their experience with the researcher, and their availability for the study.

With no prior knowledge of these individuals on the part of the researcher, the first eight people contacted by telephone who indicated a willingness to participate in the study were chosen. This group of people was composed of 4 men and 4 women. At this time an interview date and time was scheduled to meet with the interviewees in their homes. The reason the researcher interviewed only 8 participants was because after the eighth interview was conducted, most of the responses from the participants had been similar.

During the interview, about 15 minutes were spent getting acquainted and initiating a trusting relationship with the person. Following this, the purpose of the interview was reviewed and the paperwork regarding

confidentiality was presented for their signature as well as the permission to tape the session. All interviewees signed the permission forms except one person, who explained that he did not have much schooling and felt embarrassed to be taped. In his case, permission to tape was deleted from the form and his signature was gained for the interview with the researcher using written notes only. The length of time spent with each respondent averaged approximately 2 hours per interview. Two interviews were done with each of the 8 persons.

Without exception, all the interviewees were willing to talk about their experiences with hospice care. In the case of Charles, Richard, and Anne, a member of the family and/or a close friend was in attendance during the interview. It appeared that they were there for moral support and to provide a backup of memory for the interviewee. When interviewing a significant other person from each family, an unstructured interview format consisting of 12 questions which allowed for free expression by the interviewee and which encouraged them to talk about their experiences in as natural a manner as possible was used. The interview questions are located in Appendix A.

Data were gathered using individual personal interviews, and written and taped notes (with permission) were used to compile the interviewee responses. The

recorded interviews were then transcribed to facilitate data analysis. Detailed descriptions of events and conversations were recorded as soon as possible after they occurred to minimize data distortion.

A process of coding the data began shortly after the field work started. A coding system was generated inductively from the interview sessions. The following are examples of questions used to direct the inquiry of the data, "How did you feel about your loved one dying at home?" "What caregiver skills had you already learned before you decided to be a caregiver in the home?" "What other options would you have considered if you found you were physically or emotionally unable to continue caring for your loved one?" "Were you or your loved one prepared to make these decisions?" "How do you make important decisions?" The analysis of early data helped to formulate questions for subsequent interviews.

Data Analysis

WordPerfect software was used to store the data immediately after it was collected from the respondents and was used for analyzing the data. Analysis of the interviews revealed 13 areas where there was information relating to learning and decision making. These were the changed name of the interviewee, hospice care, good points,

bad points, preference, family, knowledge, beliefs, needs, others, decisions, blocks, and learning.

From the above data, case studies were formulated which outlined in thick and rich detail the aspects in the respondent's life experience which led to their ability to make decisions during the stressful and emotional time of hospice care.

For the final analysis, the 13 areas for each respondent were sorted and compared for similarities, for dissimilarities, and for unique qualities. These areas were then arranged according to the number of people having similar experiences. The totality of the interviewees' responses were then examined relative to answering the research questions in this study and the results of the study summarized.

CHAPTER 4

FAMILY CASE STUDIES

Introduction

These narratives were developed from tape recordings and note taking obtained from face-to-face interviews with family members in an attempt to give the reader a feeling for their main perceptions of living and dying and of learning and decision making for hospice care. The narratives contain a good portion, but by no means all, of the material from the tapes and notes. However, the researcher has included those portions most directly associated with the interview questions, and with those factors that made each family member's experience with decision making unique. All names have been changed to provide confidentiality.

Case Study 1--Charles

Interview Dates: August 25, 1994 and November 14, 1994.

At the time of the first interview Charles was 82 years old, and he was 83 for the second interview. He appeared in good health, and several times showed a good sense of humor and laughed easily. He was suffering from a

problem with nodules on his larynx, which later proved to be cancerous and for which he has received radiation therapy. He spoke in a very husky voice, and at times, it was necessary for him to repeat what he had said (because it was difficult to understand him). He appeared eager and willing to participate in the interview, however, and seemed glad to be able to share his thoughts and feelings with someone outside the family. The first interview focused on the learning and the decisions made during hospice care and the second interview explored the life experiences which led up to Charles's being able to make good decisions under the emotional stress of hospice and terminal illness.

His niece, Laura, who had been very close to both Charles and his wife Rose and who helped with Rose's care throughout, was present at the first interview and provided moral support for Charles. She mainly listened and provided corroboration for some of Charles's statements and took part only when it was relevant to her role in the situation. She did not attend the second interview.

The individual who had received hospice care was Rose, an 81 year old woman. She suffered from multiple sclerosis for 5 to 6 years, but the actual cause of death was listed as heart failure. The only treatment she received for the multiple sclerosis had been physical therapy and several medications. As Rose grew progressively ill, she was kept

at home and cared for by her husband, Charles, and their niece for 3 years.

Prior to Rose's illness, both Charles and Rose had experience caring for his 99 year old mother for 3 months at home, and it was not until his mother suffered two broken hips that she was placed in a nursing home for 24-hour care. She survived 10 days after being placed there; however, the family had not used hospice for her because this event happened before hospice home care was introduced to the area. Many emotions were dealt with and a number of decisions were made at that time. This experience was very helpful to Charles later when he had to make decisions regarding Rose's care.

Two months before Rose died their family doctor announced that he had done everything he could, and after consultation with another doctor the family decided to place Rose in a nursing home for around-the-clock care. At that time, the doctor suggested hospice to Charles and his niece. Charles had not heard about hospice, but after the doctor contacted hospice personnel for the family, hospice made a visit to the nursing home. They explained the program fully and told Charles and Rose what services they could provide for them.

Charles stated "I decided right then and there to accept hospice and we relied on hospice very heavily--the nurses seemed to know what they were doing. They answered

all my questions, and were courteous also." Further, he reported that as an example, one time when his wife developed a severe bladder infection in the nursing home he called the hospice nurses. "They came in and took one look at Rose, knew what she needed, put in a new catheter, and she got relief right now!" He further stated "everything about hospice was a good experience for us, and as for the bad points there were none that I know of."

During the time that Rose had been taken care of at home, she was able to help make the decisions that were needed but when she was placed in a hospice room at the nursing home, she was too ill to help make decisions. Charles reported that "my wife never said anything about going into the nursing home. She never complained and she never said she wanted to die at home. I think she knew we were completely worn out and needed a break. She always thought about others first and never wanted to be a burden on us."

The main physical need that prompted Charles to accept hospice for his wife was the fact that he was no longer physically able to care for her himself. His mental need was the need to share the responsibility of her dying with the hospice personnel, as well as with Laura. His emotional needs were met by his being able to call on hospice 24 hours a day if Rose was suffering. Anytime he called hospice they responded immediately, and he could

depend on them to help him with anything he needed, whether it was a stronger medication for Rose or he was feeling depressed and overwrought and needed to talk with someone. He reported that his spiritual needs were met by his own strong faith in God.

The main caregivers involved in caring for his wife were his niece, Laura, the hospice personnel, and the nursing home personnel. The hospice personnel consisted of registered nurses who visited every other day, or as needed, and the social worker who made several visits. The nursing home personnel were the registered nurses and the various long-term care nurses aides. Charles stated that the rest of his family only showed up occasionally, and when they did, they displayed antagonistic behavior (arguing), as well as talking about family matters to others. Charles admitted that he felt the rest of his family were only interested in his wife's will and what they could get from his family.

Charles's beliefs, as well as Rose's, included a belief in a Higher Power and an afterlife. He stated that he was not afraid of dying but was "more afraid of being alone, more or less." He said he was ready to go anytime and it would be all right with him.

During the second interview Charles admitted that some of the factors that helped him make decisions during this difficult time included various early childhood

