



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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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.

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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

experiences. When he was a small child Charles lived with his parents in Bozeman, Montana. During the depression, his mother, a licensed practical nurse, went to work at jobs that took her away from the family for 2 days to 1 week at a time. His father was a policeman on the "dry squad" whose job it was to find and apprehend bootleggers who made moonshine whiskey. He was often left home alone with his older sister and relied on her for help. Some of the chores that he was responsible for from the third grade onward were taking a grocery list to the nearby store and bringing the groceries home. He also was expected to carry in the wood and coal for the fire, shovel snow in winter, and mow the lawn in the summer. "My father jerked me out of bed one early, cold morning and said 'Get out there and get in the wood, you didn't get it in yesterday!' I certainly learned from that experience and never neglected the wood again."

His folks split up when Charles was 10 years old and after that happened, Charles said, "I kinda raised myself." He went to live with an uncle when he was 11, got expelled from school, and never went back. No one encouraged him to go back to school, as his uncle needed him to work on the ranch as "cheap labor."

From the age of 14 years, Charles said,

I was pretty much on my own. I could come and go as I pleased. If I wanted new clothes, I knew that I had to pay for them. Money and jobs were

scarce and I learned early on that I had to do it, I had to make the changes in my life.

I learned from my own mistakes more than anything else. I knew that if I did anything wrong, I would suffer for it myself. I didn't ask anyone else to help me, I made my own decisions and some were good and some were bad. I was a big, awkward kid at the age of 17 and ran around with kids 10 years older than me. I was very shy and embarrassed easily and blushed a lot. I got teased for that, of course, and I finally used sarcasm to counter it.

A tour of duty in the U.S. Navy when he was 32 further helped Charles learn self-discipline and good work habits. He worked on a secret project in Northern New Guinea repairing airplane engines during World War II.

Later, when Charles married, he found that Rose's influence settled him down and felt that he now had a partner who could help him make a good life. Charles described Rose as a lady with good common sense, a caring and beautiful person.

Another experience that helped Charles learn how to make decisions was the time, effort, and experience of caring for his 99 year old mother. This involved helping her with the activities of daily living until the last days at home when she required total 24-hour care.

Charles stated that he was definitely prepared to make the decision for hospice care for Rose. He said, "I had come to the end of my rope and there was nothing else I could do," and, as he stated, "You do what you have to do." He said what helped him the most was,

My love for Rose. She thought the same way I did, and when we bought our lots up here in Great Falls to build our home, the agreement was mutual, we both liked it. On purchases or decisions for other things we were always agreeable.

Rose did not help make the final decisions for hospice care because she was critically ill and the doctor did not expect her to live more than one night. Nonetheless, she was still able to make some decisions, because after she had been in the nursing home only a short time, she asked to have all the breathing tubes and treatments discontinued. She hated the breathing treatments and wanted them stopped. The doctor asked her if she was ready to die right then and she replied, "No, not just yet." However, when they did discontinue the oxygen and when all the tubes were removed, she lived another 2 months. Charles stated, "I believe that this was a period of time that she needed to complete some unfinished business regarding relationships in the family."

Reliance on his niece, Laura, for her love and caring was an important factor in Charles's being able to cope with the everyday decision making and emotional upsets. She was there for him to talk with and to share in the situation by giving her love and moral support when he needed it.

On the day of his wife's death, Charles was admitted to the hospital for emergency surgery for an abscessed

hernia. She died that evening. When asked how he handled that, Charles replied that his doctor "doped him up so high" that he got through the time all right. His niece, Laura, handled the funeral arrangements, which Charles's doctor allowed him to attend.

Hospice continues to support Charles by inviting him to support group meetings to help him work through the grieving process. However, Charles stated that since he had spent so much time with Rose before she died, and since he had done everything he knew how to do for her, he felt that he was now able to cope with the grieving process by himself. Further, he felt that he was being successful in his efforts to work through the process. His niece, Laura, continues to visit him regularly and gives him the extra family support he needs.

Summary

Charles believed that the following factors were instrumental in his being able to make appropriate decisions during the time Rose received hospice care. Common sense was reported to be an important factor in Charles's decision making because he said he was taught by his father from early childhood to assume responsibility for his actions. Listening to others and observing the behavior of others also provided a learning basis for his

early decision making. This he learned primarily from his parents.

His parents both worked, and he was given chores to do everyday that would seem to be harsh by today's standards. His parents' separation when he was 10 placed him in a position where he felt that he was on his own and that he had practically raised himself. These experiences in childhood forced Charles to make decisions based on his "common sense analysis" which resulted in a strengthening of his ability to make decisions later when stressed by the terminal illness of his wife.

Adversity was a constant companion for Charles because when he was left alone to make his way, he learned the necessity of pondering his problems and deciding on suitable solutions. He said he soon learned the better his decisions were, the less he would suffer. Charles reported that he had learned from his mistakes more than anything else. He was aware that he alone was responsible for his own actions, and he made his decisions based on the fact that he would suffer for his wrong decisions. Therefore, he used the successful experiences from his past to help make his everyday decisions.

Practicing the Golden Rule (do unto others as you would have others do unto you) was important in Charles's ability to make good decisions. He said he learned that treating others the way he would like to be treated worked

for him. He stressed making decisions that did not hurt others. Further, learning to give and receive graciously was reported by Charles to influence his decision making by improving his interpersonal skills and his understanding of human behavior.

Charles and Rose had a good marriage and the calming influence of Rose helped him make better decisions. Their likes and dislikes were similar and this was very helpful because it made decisions easier.

The education that Charles had was gained from the responsibilities of his early life experiences, from an eighth grade elementary education, from a tour of duty with U.S. Navy, and from the experience gained from his lifelong job as a welder. The lessons of responsibility, persistence, and integrity that he had learned earlier proved to be quite valuable. Later he was required to make important decisions in the U.S. Navy, on the job, and in the recent past when decisions needed to be made regarding hospice care.

Charles' niece, Laura, was the family member who was the main support for Charles during hospice care. She was there for him when he needed to discuss problems. She helped him explore alternative solutions and helped him make the final decisions. Her wisdom and counsel were a stabilizing influence and were instrumental in helping Charles stay calm in the times of great emotional stress.

This family support allowed him to make better decisions as well as gave him moral support.

Case Study 2--Richard

Interview Dates: August 26, 1994 and November 18, 1994.

Richard, 84 years old, was the caregiver for his wife, Emily, who was 82 years old. The primary interview focused on the hospice care situation and the decision making required, and the follow-up interview investigated the prior life experiences of the caregiver.

Emily had been diagnosed with colon cancer which had metastasized to the stomach. As Richard reported it, "She literally starved to death." Emily had many friends who had suffered greatly from the treatment of cancer by chemotherapy; therefore, she refused chemotherapy treatment when approached by her doctor. From the time of her diagnosis to the time of her death was a period of only 10 months. Her doctor had repeatedly suggested that she have tests done earlier, but she refused to do so for reasons known only to her.

Following surgery in May 1993, Emily's doctor told her that he was "definitely sure that some cancer was still left in there." He explained that "cancer is like a tree that sends out roots and these roots expanded to the point where I was not able to get all of them." The doctor explained everything well and in an understandable way, and

he told Richard and Emily that Emily most likely had from 8 months to 1 year left to live. As it turned out, she lived 10 months from this time. She died in March 1994. Her previous health history showed that she had suffered from chronic colitis for at least 20 years.

The only treatment that Emily would accept was special vitamins, minerals, and pain killer medications. She tried physical therapy briefly for back pain, but since it increased the pain in her hips, it was discontinued. Emily wanted to stay home as long as she could, so she was cared for at home by her husband, her daughter, and her son-in-law up until the last month of her life.

Richard and his family had never heard of hospice care at this time; therefore, their doctor contacted hospice and asked them to see the family at their home. Emily was capable of making the decision for hospice care and signed the papers. All options were considered and she and the family chose what was best for her well-being and what would give her as much relief from pain as possible. The only other alternative would have been the hospital or a long-term care facility, but they did not want that. Emily was admitted to hospice care 21 days before she died.

The hospice care personnel visited the next day with Emily and her family and explained the services they could provide. As Richard stated,

They were cooperative in all our dealings, they got equipment such as a hospital bed, a wheelchair, and other supplies for us when we needed it. Medicare and our Medicare supplemental insurance policy covered all the expenses for us. The way it turned out, we made the right decision to have hospice, and it was the proper thing to do.

Richard had only positive comments to make regarding the hospice care his wife received. The only comment he added, though, was that he wondered who it is that notifies the doctor about terminally ill cases, as he felt that his family could have used hospice 1 month to 6 weeks earlier than they did. Before hospice,

Emily's pain medications were not strong enough, and I didn't really understand what was going on, so she suffered a lot because of this. I just wish we could have gotten hospice sooner because they could have helped her with stronger medicines.

The 24-hour care that hospice afforded the family was well received. Richard and his family knew nothing about hospice beforehand, but after the program was explained they accepted it wholeheartedly. As stated, "It could have been a little earlier, though." All family members accepted hospice because they needed the help and support hospice provided. They felt that hospice was very thorough. Richard admitted to being a good dishwasher but did not know much about cooking, so his daughter and hospice workers helped with this.

Hospice met his physical needs by offering more services to his wife than the family was able to give her.

Hospice furnished needed equipment and the family knew they were there 24 hours a day to help them. If they needed a change in pain medication or if the doctor needed to be contacted when Emily was unable to sleep at night, help was available. In addition, hospice met the family's mental needs by easing their minds when they assumed part of the responsibility for the care of Emily. The social worker from hospice assisted in helping meet their emotional needs by making two visits to the family home. The family stated that she was interesting to talk with, she helped the children, she helped Richard adjust, and generally speaking "these trained people guided us through all the steps."

Richard's son-in-law is the pastor of a local church and helped with the spiritual needs of the family; however, the family agreed that "Mother was a spiritual giant through the whole thing." Altogether, hospice helped Richard's family for 3 weeks.

In addition to hospice workers, Richard was assisted in Emily's care at home by his daughter and son-in-law and by several friends who provided food and flowers while she was ill. This was important to Emily because she loved flowers and they cheered her considerably.

Although Emily desperately wanted to stay at home as long as she could and remained oriented until the day she died, near the end she realized that her caregivers were wearing out physically and emotionally and badly needed a

respite. A respite room in a nursing home was used for Emily's last 2 days, when the family became physically and emotionally "burned out." Even then, Richard and his son-in-law took shifts staying with Emily in the nursing home.

At the time of Emily's death, Richard had just gone home but his daughter had stayed and was with her. Hospice was notified and came at once. They took care of the details at the nursing home and stayed with the daughter, which she said was a great comfort to her. Richard stated that he felt sad about not being there when Emily died but was glad his daughter had been with her. His daughter continues to be a source of strength and comfort to Richard and was in attendance during the first interview. She did not attend the second interview.

Hospice also met the needs of their sons who lived out of town by sending letters and informative materials which explained the program and offered suggestions for dealing with the loss of a loved one. The daughter stated that because of hospice and their help, she was able to accept the fact that her mother was terminal; before then she had been in denial. This help extended to the period following her mother's death by taking advantage of support group help and counseling from hospice. In addition, hospice has helped Richard's two sons and his daughter's five children. The one son not living in the area suffered from denial and guilt and was helped after their mother's death by

follow-up counseling from hospice personnel, who suggested ways for him to work through his grief.

The follow-up services that hospice extended to the grieving individuals in this family have been greatly appreciated. This help has mainly been in the form of frequent letters and information bulletins which suggest ways that the grieving process can be successfully worked through.

Richard's attitudes and beliefs that have been important to him and helpful for making decisions included being a born-again Christian. He stated that he felt that there was no reason why he would not be going to heaven, and he was looking forward to being with his wife again. He reported that he was not afraid of death, but was "afraid of suffering, mostly." He stated that in his 84 plus years he had been and was now richly blessed.

Richard stated that he was able to make the decision easily for hospice care because he had not had much experience dealing with terminal illness and needed the extra help. He stated that, "They offered it in a manner that covered our needs very much."

One factor that helped Richard make decisions was praying about it, asking the Lord's guidance for any important question. I wanted to do the right thing that was acceptable to the Lord and all else. When I was young, I also attended Bible School when I could in the summer and learned about the moral right and wrongs, which has helped me a lot all through my life.

No blocks or hindrances for using hospice care were expressed by Richard. He stated that under great emotional stress he also relied on his children to help make decisions, as he values their opinions.

Richard's history for decision making started when he was born and raised in the 1930s on a farm during the Great Depression and the drought in North Dakota. His mother died when he was 6 years old and from then on he had to make certain decisions on his own. His dad homesteaded the farm and Richard was the oldest of four brothers. His dad had said, "A farmer doesn't need more than an eighth grade education to run a farm. You're supposed to take over the farm later on." Some of the responsibilities that Richard had as a 6 year old included helping with the chores; at 8 years old he helped with milking the cows, feeding calves, caring for the chickens, and when the hens were brooding he had to take the eggs away from them. This required real courage on his part since the hens did not want to part with eggs they were trying to hatch. From the ages of 9 to 10 years he helped haul in hay and haul out manure in addition to many other chores.

Richard's father was a leader in the community as a member of the Township Board, the School Board, and the Community Club, and was so occupied that Richard stated,

He would often leave decisions to me even as a child. I didn't always make the right decision, either. My motto was to never make a quick

decision, analyze the matter first, get a picture of what you wanted, and then do it the best way possible. This worked best for me.

He called this "using my common sense" and regarded it as one of his most valuable attributes.

Richard stated that he liked school and started out in a one-room schoolhouse one mile from his home. He attended this school for the first 2 years, then attended a new consolidated school in the little town of Hamlet, North Dakota, for the next six years. Richard recalled that he had a very good teacher in the fourth grade who helped all the students with their problems, and who really "understood us." However, another teacher a year before kept a rubber hose in her desk, "and if we didn't behave, she hit the students across the hands. I got the rubber hose only one time," Richard reported, "when in the spring of the year and outside the school I hit a girl in the face with a snowball. I got called in to see the teacher and got the rubber hose on my hands. It really taught me not to throw snowballs at girls!"

After Richard finished the eighth grade, he attended high school from November to March in order to learn more. He did not take any exams and did not earn a high school diploma, but he got 1/4 credit each year for playing basketball when he was 15 years old. He later enrolled in the International Accounting Society and worked on those lessons all winter, getting all As and Bs. He always

wanted to become a CPA, but never had enough education for this.

The advice he received from his father came mainly in the spring of the year when his dad wanted a certain crop planted.

He told me how to prepare the ground, plow, drag, and seed it if the ground was loose enough. I also had the responsibility for six horses on the plow and four horses on the drag. I had to feed the horses and haul the manure out, milk five or six cows, and get the cream in the cream can. We lived on a little branch line for the railroad, and had to have the cream at the depot at a certain time each night. We sold cream or butter in the summer for cash, and eggs and butter were traded for groceries when we went into town.

At 14 years old, Richard related,

I did all the farm work for the next 2 years, got my clothing, board and room, and spending money for Saturday nights. I figured that I'd get the farm, but my next younger brother wanted to be a farmer, so he got it.

Richard hired out at 16 years old to a neighbor with a two-man spread near a place called Big Meadow in Montana. When drought hit, the land dried up. He worked there for 4 years and during that time there were no good crops. He did make enough money, however, to buy an old 1928 Model T Ford. He then left this job to work for another rancher for 2 years. He made board, room, laundry, and \$10.00 a month for the next 4 months. He related that he was very proud of himself at that time as he had managed to still have \$18.00 out of \$30.00 left at the end of 3 months.

Following this, Richard took a grain elevator job and started the courses in accounting and bookkeeping.

In this job with the Line Company grain elevator, they made all the decisions for me. I kept the books and records, graded the grain properly, and made sure we shipped out the same quality we had paid for.

My next job, though, was with the Farmer's co-op elevator in Culbertson, Montana. I made all the major decisions there from grading factors to all the big decisions. Yes, all the big decisions were up to me. One main thing I had to remember was not to pay more for grain than I could get for it. If I didn't make the right decision, I tried to rectify it to the best of my ability. If it involved other human beings, I would apologize and let them know I was wrong. If given a job to do, I would always complete it.

Altogether, Richard worked in the grain elevator business for 30 years.

At the age of 84, Richard is still doing tax returns for family members and friends. He is mentally alert, physically active, and maintains an apartment in town by himself.

Summary

The foregoing responsibilities and experiences have contributed to Richard's decision making ability. The early childhood responsibilities that were expected of Richard on the farm from age 6 were tremendous. Added to that was the death of his mother at about the same time. This forced him to make more decisions for himself. Reflecting on this in later life, Richard was glad that his

family had encouraged him to make his own decisions from the beginning.

Being a good listener and asking questions of adults when he did not understand something were very helpful in learning how to make decisions. Learning from others' experiences, whether good or bad, was important to Richard. Maintaining a positive "can do" attitude and learning from his mistakes enabled him to focus on possible solutions to problems instead of the problem itself.

The necessity of becoming a responsible person at a very early age due to family circumstances literally forced Richard to learn to make decisions. He called this "using my common sense" and regards it as one of his most valuable attributes.

General life experiences which included working as a ranch hand, learning accounting and bookkeeping skills, and being in charge of a large grain elevator in Montana were seen as valuable for the decision making process. The competition from others in the grain elevator business was also reported to be a very useful factor. Important financial consequences in business necessitated that Richard make good decisions at all times to avoid losing money.

And finally, learning about moral values as a youth in summer Bible School was mentioned as one of the most helpful factors for decision making throughout Richard's

life. Establishing values of right and wrong made it easier for him to make choices later. Richard's faith in God, as well as his wife's great spiritual faith, contributed to their ability to make decisions. He reported that on very important decisions he would pray for guidance, and that he always got the help he needed. He maintained that his faith was especially vital in his being able to make good decisions during the stressful times of hospice care and further emphasized that he practiced the Golden Rule because it had helped him all his life.

Case Study 3--Joseph

Interview Dates: August 26, 1994 and November 18, 1994.

Joseph, 52 years old, was the caregiver for his father, Willard, age 73 , who suffered from leukemia for 8 1/2 months. The primary interview concerned the caregiver in the hospice care situation. The second interview focused on the prior life experiences and formal and informal learning that took place in the caregiver prior to hospice that led to his ability to make good decisions.

Willard's illness was short-lived and the treatment used included 40 blood transfusions, in-line morphine pump for pain, and a bone marrow procedure. The family was referred to hospice personnel by their family doctor. The family was familiar with the word "hospice," but they did

not know what services hospice provided until one of the hospice nurses made a visit to the home. Some of the positive points mentioned by Joseph were that the nurses were very helpful at all times. They checked Willard's vital signs regularly and briefed the family on the services and the equipment that hospice would furnish when it was needed. Joseph also said that the nurses and all the hospice staff were good listeners, were easy to talk to, and were a source of reassurance for Joseph about the care of his father.

This was particularly important since Joseph is a paraplegic who has been in a wheelchair for 35 years. At first, the hospice personnel did not believe that Joseph would be able to adequately care for his father, but when they learned that he had previously helped care for his mother, they agreed to work with him as the main caregiver. In addition to his personal care skills, he was able to do the important and needed tasks of cooking, cleaning, and shopping from his wheelchair.

After Willard was told by his doctor that his illness was terminal and that hospice would be available to him, he accepted it because he said they needed the extra help. Joseph's brother did not want to do personal care for his father, but did occasionally shop for groceries and visited his father about 30 minutes each day. Joseph stated that he thought his brother suffered from denial. Hospice

provided information to his brother on terminal illness, which seemed to help. However, the main care of Willard was done by Joseph and by his 11 year old niece, who had previously helped when her grandmother was ill. She was a great source of help and moral support for Joseph while he cared for his father.

Willard wanted to stay at home "until the last minute" and said he "perhaps wanted hospital at the very end of life." He felt that he could live a better quality life in his own environment. From the beginning, the family welcomed the hospice help. They looked upon it as a new venture with everything taken care of by hospice, especially the excessive paperwork. They had Medicare and a supplemental insurance policy which paid for all the medications, care, and treatments.

Joseph's physical needs were met by the hospice nursing staff when they "checked Dad out and did what needed to be done that I could not do." His mental needs were met by hospice providing the shared responsibility and reassurance and by Medicare and the supplemental policy paying the bills. This also reduced his stress and worry. His emotional needs were met by his observing the Golden Rule and by treating others well. Finally, his spiritual needs were helped by his Lutheran pastor, the hospice social worker, and his many friends.

Although Joseph was the sole caregiver, hospice helped when necessary. "No other options were considered, none. I wanted to do it myself for Dad. He had a living will."

Joseph was able to make all important decisions and even was able to make the final decision for his father when he went into the hospital. There he went into a coma the next day. The doctor discontinued everything except the morphine and "let him slip away in 2 days. Our doctor helped make some decisions, especially at the last on the major medical decisions. We were in agreement." There were no blocks reported by Joseph when helping make the major decisions for his father's care.

Joseph said he had learned a lot the last time he had helped care for his mother, and that he thought that there were worse things than death. He said he thought suffering may be worse than death. He further stated that he has no fear of death and that the afterlife may be better than what we now have. He did remark that he had several unusual experiences since his father's death. Once, shortly after his father's death, he came home, locked the doors, went to bed, and when he woke up the next morning the doors were wide open. Another time he went to town, having locked the doors, and when he got home the doors were unlocked again. He also reported that one night at 4:00 a.m. his reacher, an appliance which he uses to pick up objects, flew over the floor. A week later, a

silhouette appeared in the house, his dog wagged his tail at the apparition, his phone rang and the answering machine answered. Joseph said he felt that his father was trying to let him know that he was still alive somewhere and that he was all right.

The life history of Joseph is rather meaningful and has included some of the following aspects. Between the ages of 2 to 7 years, he was very active. He "ran away a lot from 2 to 4 years old" and later attended school. His family moved several times, but until the age of 4 he lived on a farm with his parents. His main activity at this age was going on errands for his mother.

Then his family moved to Garrison, North Dakota, where his father worked on the Garrison Dam and his mother taught in the country school. His mother taught at his school when he was in the first grade. Joseph recalled that most students came to school by horses and wagons in the summer and horses and sleighs in the winter, as well as a few students who used skis to get to school.

Very suddenly, at the age of 7, Joseph discovered that he could not walk well. He fell down or needed to hang onto two chairs to get around. This lasted for 2 months. Then the condition went away and he managed to walk by himself until the sixth grade. At the age of 12, he had a recurrence of falling frequently, hanging onto walls, experiencing pain in his back and stomach area, and not

being able to sleep well. Again he went into remission and was well until he was in the eighth grade or about 14 years old. At this time his symptoms returned, but now his legs were stiff and he needed crutches to walk. He still had feeling in his legs but his condition gradually got worse. He used crutches until he was 16, at which time he started losing feeling in his toes and ankles.

His doctor in North Dakota did tests and found that among other things he had a low hemoglobin of 4 milligrams, and the doctor ordered numerous blood transfusions. Subsequently, he had surgery of 6 hours duration, which removed a cyst-type tumor from the spine. The doctor had to cut the spinal cord to relieve the pressure, and so at the age of 17 years Joseph was told that he would be unable to walk again. His case was very unusual because of the rare type tumor, and Joseph became a celebrity of sorts. He was photographed and written up in a number of major national medical journals.

Joseph reported that at this time of his life other folks helped with some decisions. His own decision was that he did not want to live. Then the doctor said something that "made me mad, and I decided to live just to prove him wrong." Once he made up his mind to live, his parents would not help him at first, but "watched to see what I could or could not do, and if I could do it, that help stopped. It made me very independent."

His schooling included a private school, where he graduated in 2 years. Then he earned an Associate degree from the University of Oklahoma where he majored in technical work, precision work, aircraft technology, clerical work, and office work. This led to a job in North Dakota, and later to Wichita, Kansas. At this time, companies had just started hiring the handicapped, much of industry was going strong, and he worked with the aircraft industry for several years. Joseph stated that during the war in Vietnam, attitudes had changed toward hiring the handicapped due to the numbers of wounded servicemen coming home. From Wichita he went to Gillette, Wyoming, where he worked for the police department and for the gas company. From Gillette, he moved to Great Falls, Montana.

At this time his mother was diagnosed with cancer, and for 7 years he was supportive of her and helped with her care.

Mom never took chemotherapy. She made her decisions, and Dad and I backed her 100%. The doctor wanted to override her decision for chemotherapy, but she did not want it and wanted to stay home. She assumed that Dad and I would take care of her, which we did.

Four years after her death, his father contracted leukemia, another form of cancer. Again, the decision as to whether or not to take chemotherapy was made by his father.

When asked by the doctor if I thought my Dad should take chemo, I said that it is up to Dad.

He will make the decision, and whatever he decides is what we will do. I will not take his decision making away from him.

And Joseph further stated, "He was in charge of his life until the very end. Dad was independent, he wanted to do it himself." His father also refused chemotherapy treatment and wanted to die at home. With the help of hospice, Joseph cared for his father throughout his illness.

After his father died, Joseph knew that he needed to make some changes in his living quarters. He disposed of the large furniture and purchased smaller furniture so he could get around better in his wheelchair. He changed his father's bedroom into a den, and then he made major changes in his life. He volunteered once a week at hospice, did lavish cooking at both Thanksgiving and Christmas, and had many friends over for the holiday festivities. He reported that he had learned to cook as a child and had learned to survive when alone.

In retrospect, Joseph stated that he had learned much from his family as his family did not hide tragedy from the children, and his folks talked openly about illness and death. Their motto was:

Set down and think about it, dying is part of life, and you should treat other people like you would like to be treated. You can do just about anything, go through anything if you have to, but you must control your own senses. Mother was a very strong lady and was always open to talking about death.

Joseph lost three great grandparents at 4 years old. He also had an aunt who took care of five people when she was younger. She always said,

We must be strong, be there. Others are first, I am second. She encouraged others and helped many friends and relatives. She was ahead of her time. She is still living and is now 90 years old and I am 52. We are both alone. She is in Texas and we write back and forth and help each other.

At the present time, Joseph reported that he has everything in order, just where I want it to be. I volunteer one day a week at hospice, I am flexible, I attend hockey games, baseball games, and concerts. However, I do get disturbed when they sometimes put my wheelchair 400 feet away from the stage during a concert, but I am working to improve on that situation.

Summary

In summary, the lessons that Joseph learned that helped him make important decisions, and especially decisions under stress, included the necessity of having to do so at the very young age of 7. Early childhood experiences when living on a farm provided Joseph with many opportunities, such as helping care for the animals. From these chores he learned to take responsibility for himself and learned to make decisions that directly affected himself and others. Watching, listening, and following his parents' examples were mainly used at this time.

Listening and learning from his very decisive mother was considered helpful because she spoke openly about the

important issues of life and death. She was also a school teacher and taught him during his first few grades. She exhibited a certain strength under pressure that served as a particularly important model for him.

The deaths of several members of his family when he was very young and his family's reactions to those deaths provided valuable learning situations in his life experience. His family accepted the deaths as a normal part of life. He used the experiences with death and dying he had as a child and applied what he had learned when he cared for his father in hospice.

Recovery from a spinal tumor operation that left him paralyzed from the waist down and dependent on a wheelchair for mobility was instrumental in teaching Joseph many things. Among the characteristics that were learned was a keen sense of independence, a firm determination to overcome all obstacles, a decision to focus on the positive aspects of life that were left to him, and a decision to make the most of them. Although Joseph was the victim of a crippling condition, he was not catered to but was encouraged to consider all the options at hand in order to make his own decisions. This sense of independence has proved valuable to him in many ways throughout his life.

One of his first important decisions was the decision to continue to live following his major surgery at age 17. His reaction to something his doctor said precipitated this

decision, which was actually made in defiance of the authority of the doctor.

After mending from the surgery and his completion of schooling, Joseph's work in the technical field was considered important in his learning process. This work was demanding, detailed, and tedious and it required him to make daily decisions of importance. His ability, learned in childhood, to assume responsibility for his own thoughts and actions was a definite asset to him.

Joseph considered the Golden Rule as his guideline for working with others and stated that he "found it a practical tool, not only in my learning to make decisions but in my caring for other people." Helping in the care of his mother during a terminal illness, and then later caring for his father with the help of hospice, provided situations in which Joseph learned the value of including others in the decision-making process by considering their wants and needs first.

Finally, his aunt, who was such a powerful model of strength, courage, and caring when he was a child, is still living. She stays in contact with Joseph and continues to inspire him by her strength and her determination to overcome all odds, even in old age.

Although Joseph was the victim of a crippling condition, he was not catered to but was encouraged to consider all the options at hand in order to make his own

decisions. This ability to learn from others and from his life experiences has been very useful for Joseph. What appears to make the difference in the quality of life and the independence that he now enjoys is his ability to utilize the good decisions he has made in the past to help make his present decisions.

Case Study 4--Fred

Interview Dates: August 29, 1994 and November 29, 1994.

Fred, 84 years old, was the main caregiver for his wife, Ella, age 83, who was diagnosed as having cancer of the colon. The first interview dealt with the caregiver and his wife during the time decisions needed to be made regarding hospice. The second interview investigated the history and prior learning experiences of the caregiver which helped him make decisions during the period of hospice care.

When the cancer was discovered, a surgical procedure known as a colostomy was done, and for a short time Ella's health was good; then the cancer returned. Chemotherapy treatment was ordered for her, but she did not accept it because Fred was in the hospital with a heart attack. When Fred returned home, Ella decided not to undergo the treatment that the doctor recommended because she said she did not want the extra pain the treatment caused. (The total length of her illness was 3 years.) According to

Fred, his wife had never seen a doctor before she was 60 years old.

After the operation, the doctor told Ella that he could not get all of the cancer and suggested that the family use hospice services. A nurse in the doctor's office explained the concept of hospice to them. Hospice was unknown to Fred and Ella and their family. The first time they learned about it was when they noticed an article in the local newspaper stating that two well known people had died and had requested that donations be made to hospice in lieu of flowers.

The family accepted hospice, and a nurse from Peace Hospice of Montana was sent into the home to further explain the program and to arrange for the care of Ella. The positive points listed by Fred were,

They saved us money, and she got to stay home where she wanted to be. One night in that hospital and she was ready to come home the next day. The nurses came in the home, helped with the catheter, got us a hospital bed, and electric lift, and pain medicines. When we needed a nurse, they never missed, they were right here.

As far as bad points of hospice were concerned, Fred reported that "there was not a bad nurse at no time; in the hospital or in hospice. I can't say enough good about them."

Ella wanted hospice because she wanted to die at home. In fact, the idea was so acceptable to her and to Fred that they talked about it with other family members. Often, the

family members visited when the nurse was giving care in the home. These family members consisted of his brothers and their wives from Havre and Helena, as well as Ella's sister and her husband from Big Sandy.

Although Fred had no knowledge about hospice beforehand, he reported, "I figured she was right where she wanted to be--at home. It was almost too good to be true, such a good deal to have hospice." Fred did some cooking, but mainly did the cleaning and shopping. His wife did most of the cooking herself until one day when she came to the kitchen without her walker. "She fell on her butt, and was spooked after that. She only used the walker near the end, but after the fall she went a little faster," Fred stated. "The nurses gave us all the information we needed, and left some papers for us to read." His wife died at home March 31, 1994, at 1:15 a.m. Fred said, "It was a peaceful death. Her Dad died of a heart attack in his sleep, and she wanted to go that way too." Ella had been on hospice care for over one year.

When examining Fred's beliefs, he reported, "When you need to use your faith, you do." He told how Ella did not believe in churches, but she believed that "one should just do what she knew was right." Although Fred was baptized a Catholic, he said that the older he was, the less he believed in it; especially confession and the service. He

said the priests used only Latin and he did not know what they were saying most of the time.

The physical needs of this family were served by their being able to call hospice 24 hours a day and getting a prompt response. Mental needs were met because "it eased my mind, I ain't alone." Emotional needs were helped by having other family members and hospice workers who cared and helped out. They took care of their own spiritual needs, according to Fred.

The only other alternatives for Ella's care that were considered by the family were the hiring of a home care nurse or placing Ella in a nursing home. However, the final choice was made for hospice care because she could stay at home. Fred's son and his wife also helped with her care.

The decision to have hospice care was made by both Ella and Fred. As Fred said,

At other times, though, I always said think about it, how it's going to turn out, I was thinking about it when I was in bed. I looked at it from different angles and then I would take the option I thought was the right way. I learned this from rebuilding farm machinery and getting ideas for farm machinery from other farmers.

Fred confirmed that he always worked with his wife when making decisions, and that the partnership of marriage was very helpful to him. She had an eighth grade education, and he said that she made up for his lack in the area of numbers and keeping books.

A block experienced by Fred when making decisions was expressed as "always something that's holding up progress." He expressed regret that he had very little education--three years in North Dakota. He said he felt that his lack of education was a great hindrance to him and he frequently blamed the many hardships of his younger life for many of his present problems. In some ways he still lived in the past when he said, "One winter all we had to eat was bread and lard."

At another time when trying to decide whether or not to buy land, he and Ella decided to buy her parents' place. He said he had to talk Ella into it, but they paid it off and were glad to have it for their two boys later on. However, the boys had other ideas. As Fred stated, "The boys were all right until after high school, then away they went. They didn't want the farm."

Some of the Fred's life history explains how he learned to make decisions, especially decisions made under stressful conditions. Fred was born August 11, 1910, in Botunu, North Dakota. His parents were farmers and his mother was a hard worker, but his father was not a worker. As Fred stated,

My Dad was worthless; he didn't like to work. They claim his folks had money and he didn't learn how to work. When Dad got married, his folks gave him \$5,000. He bought a tractor, but he never did use it because he didn't like to work.

Fred started school at age 6, and he recalled that he had to sit in the same seat with a girl. Ordinarily, he could not start school in the fall because he had to help with the farm work. He quit in the spring to help with work again. Often he could not go to school in the winter because the snow was too deep. However, in spite of these obstacles, Fred was able to complete the third grade.

At the age of 6 years, in addition to school, he had many responsibilities. He fed horses, ran them in, cleaned out the barn, milked cows, and pulled weeds out of garden. He said that they all worked together to feed the family, but that his father did not help much.

At 10 years of age, and no longer in school, he worked with a threshing crew from North Dakota. These men, he stated, were "rough men who drank heavy, didn't know how to put a harness on a horse, and told dirty stories." Fred related how he often went to sleep listening to the stories.

In the morning when we got up there were still more stories. In the evening we gambled and played poker. They figured if a kid was old enough to work, he was old enough to play poker. I didn't gamble more than penny ante. This was the time of prohibition and moonshine stills were located in sloughs all over North Dakota. The revenuers didn't bother us, and we didn't bother them.

In the spring of 1928, the lakes in North Dakota went dry from the drought and many people left the area. Fred bought an old car from a junkyard for \$15.00. He fixed it

up, and it brought him, his mother, and the five younger children to Big Sandy, Montana, to their aunt and uncle's place. The coal mines were open and working. As Fred reported,

Dad didn't come out here at all. Mom and the five kids younger than I was and one older sister got here one afternoon. Our uncle worked in the coal mine, so I walked over there with him and got a job digging ditch for the Carbide Company. I worked there all fall and winter and in the spring my brother went to work at one ranch and I went to another one. We worked there for 5 years at \$30 to \$40 a month.

In his early 20s, after working on a ranch for several years, one of the mine bosses retired and wanted Fred to run his coal mines. He leased them to him and as Fred said,

I had to learn a hell of a lot in a hurry. I bought machinery and ran two mines all during World War II. From Big Sandy to Chinook they mined coal. All the young guys got drafted into the military, and my partner wanted to go in the service but he couldn't because we needed him right there. We worked night and day to keep people from freezing in the winter, but then when stove fuel oil went to 7 cents per gallon, people quit using coal and there went our business.

One of the challenges Fred experienced during this time was learning how to keep books. His partner was good at adding, he said, and taught Fred how to keep the records for the business of the mines.

During his married life, his wife kept house and kept the books, but now that she is gone, he has had to keep the books himself. He reported that he usually made the

difficult family decisions during the time he was married to Ella. He said that he had started making decisions when he was very young. "Just make them" is his motto and he still uses this idea as he makes his decisions. He said the sooner he made decisions after looking at the options, the sooner he knew if the decision was a good one. If the decision proved to be a bad one, he changed it right away.

Summary

Fred's early life experiences and responsibilities laid a solid foundation for his being able to make good decisions later under stressful conditions. He learned these lessons in a very practical, informal way--by doing.

Since his father did not like to work, and since there were five younger children in the family, Fred was given heavy responsibilities starting as a child. His family was extremely poor and they all had to work together to provide the food and shelter to keep them alive. The family was growing up during the Great Depression, which explains why the times were so difficult.

He affirmed that his mother was a good worker and he learned from her how to work and how to be a responsible person. Many decisions were made every day in the course of his work on the farm and later in the mines. He learned from his experiences when he was a small child that he had to rely on himself for many things. This proved to be a

valuable asset to him later. He drew knowledge from his past experiences and used it in his life and work.

After he married, he relied on Ella to help him with any knowledge that he had not experienced firsthand. She had completed more schooling than he, and was good at reading, writing, and arithmetic. He also discussed his most important issues and problems with her and had the benefit of her feedback when making decisions. His marriage partner was indeed an important factor in his ability to make decisions, because she bolstered his self confidence and made decision making not only easier but more successful for him.

The mine businesses that he ran for so many years contributed to his experiences that taught him how to make good decisions. In order to stay in business, he learned to make decisions that made money for him. He also learned how to supervise and work with his employees by using his skills from working with people in the past.

Finally, managing a farm for the past 20 years has required many instances of decision making. Fred has used his life experiences as his school of learning. This ability to take knowledge from his past and apply it when it was needed was the element that he said helped him make decisions during the emotionally stressful time of his wife's hospice care.

Case Study 5--Ellen

Interview Dates: August 30, 1994 and November 30, 1994.

The caregiver in this case was Ellen, 77 years old, whose husband Edward was diagnosed with cancer of the prostate at age 74. The initial part of the case study centers about the hospice client and the learning that led to decisions needed for hospice care. The second part of the case study focuses on the history and learning experiences of the caregiver prior to using hospice.

A malignancy was first discovered by Edward's doctor in 1980. A second opinion was needed, so Edward was sent to a clinic in Seattle to see a specialist. A series of 40 radiation treatments were administered. The specialist stated that the reason the cancer had been discovered was because Edward went every year for a routine checkup. He was sent home following the extensive radiation therapy, and was well for approximately 10 years.

In September 1990, Edward felt back pain and went to a chiropractor for 3 weeks for treatment, with no improvement. After a visit to his doctor, and more tests, it was found that the cancer had metastasized to his bones. Between 1990 and 1993 a lump appeared on his cheek and radiation was again given with good results. During this entire time, Ellen stated, the doctor did not tell her that her husband was terminally ill.

In this case, the doctor did not contact hospice; Ellen did. Ellen had initially learned about hospice from her daughter, Corrine, who was a volunteer with hospice and had spent a great deal of time with dying patients. She was a harpist and played music for them during their final days.

When the hospice nurse went to the home, she told Ellen that Edward probably had only 2 weeks to live. The family accepted hospice and were very open to learning about the care it provided. Information about hospice was furnished by the hospice nurse, and hospice booklets were left in the home for them to read. Ellen and Edward were glad to get the information, and together they decided to accept the help because both wanted for Edward to die at home, as he wished.

Their son and daughter had some problems when they worked with their father, so the hospice nurse talked with them and it appeared to help. Ellen wanted him to die at home so she could spend more time with him, and she especially wanted to be with him at the end. She reported that she wanted to be there to "release him to go on."

One of the good points about hospice that was mentioned by Ellen was the honesty she received from the hospice nurse regarding the time her husband had to live. Her husband wanted to die at home or, if need be, in the hospital. Ellen reported that she was very satisfied with

the hospice help. They provided aides who helped with bathing and provided nurses who helped with medications for pain. They sent volunteers who sat with him and gave Ellen respite occasionally, and they provided liquid nourishment for him when he was no longer able to eat solid foods. In addition, a wheelchair was provided for mobility when he was unable to walk. Although Ellen had no negative comments to offer, she did say she was thinking of some suggestions that may later prove helpful for others in the same situation.

Regarding knowledge about hospice prior to its use, Ellen said that she and her family members had not known much about hospice but were happy to know there was such an organization. Ellen had never experienced death first hand, and she had only hearsay about hospice from others; therefore, she welcomed the help and support that hospice gave.

She had, however, extensive knowledge and experience with cooking, cleaning, shopping, meal preparation, reading, and personal care. She was able to help Edward in and out of the tub, and she did his personal care when hospice was not in the home.

During his illness, Edward had requested that no machines be used to keep him alive. He did not want to be a burden to his wife and children and said he had no fear of dying. Ellen reported that he was a Christian and had

great faith. He believed in an afterlife and said that death for him meant no more suffering or pain. He had said, "We know we must go through this life."

The physical needs of the family were met by personnel that helped with his care every day when they bathed him and helped him move around. Their mental and emotional needs were met when hospice provided moral support for the family by being on call 24 hours a day. The nurses called the doctor if pain medications were ineffective, and volunteers delivered supplies and medications directly to their home. This saved them many trips into town, as they lived in the country. Finally, their spiritual needs were met by counselling with their own pastor.

Others who assisted in the care of Edward, in addition to their son and daughter, were her sister, Anne, and neighbors and friends. Options that were considered besides hospice were to ask their daughter for more help, to move him into a nursing home, or to place him in a hospice room in the hospital.

Since Edward was so ill, the final decision to have hospice was made by Ellen. She said that it was all right with her husband, since he told her he wanted to stay home. She said having hospice helped with their finances, because they had Medicare and a supplemental policy which paid all the bills. He died at the age of 84. He had a peaceful

ending, with his wife and daughter in attendance. His last words were, "I'm going home."

What helped Ellen the most during this time? She reported that being able to call someone and talk to them and get a quick response was very important. When asked how she made important decisions, she replied,

I think about them, pray about them, and talk to others. The actual steps I take are:

- (1) Something has to be done. (2) I have to do it. (3) How will it affect my and others' life?
- (4) Look at all the options, sort them out.
- (5) Choose the best one and make the decision quickly.

No blocks were experienced by Ellen when making decisions.

The early history of Ellen's life demonstrated how she learned to be a decision maker. She was born in 1918 at Fairfield Bench Community, 3 months following her father's death in a car accident. He was only 37 years old.

She then lived with her mother and her older sister in a little two-bedroom house. Ellen related how all three of them slept in a double bed in the living room of the house. As a child of 4 years, she was expected to help keep a fire going in a small round pot-bellied stove, their main source of heat in the winter. She recalled watching the reflections of light from the stove on the ceiling at night and feeling "cozy and secure."

Her mother had a pump organ that she played in the evening after the work was finished and the children were in bed. Ellen remembered she and her sister sneaked out of

bed and sat beside her listening to the beautiful music. Her mother was so engrossed in the music that she often was unaware of their presence while she played. These were hard but happy times for the family.

Ellen's grandparents lived near them, and it was often her duty to take a lard can filled with coffee and sweets out to her grandfather when he worked in the fields. She enjoyed doing this because she was always rewarded with an extra cookie.

At the age of 6, the family moved about 3 miles from her grandparents to a farm that Ellen's father had homesteaded in 1913. She was now in the first grade. She walked a mile to a country school along with her sister and an older neighbor boy. The winters were brutally cold and Ellen recalled wearing black knitted stockings, cap, and mittens made by her mother when she went to school.

As she grew older, at the age of 8, one of her responsibilities was to build a fire in the kitchen stove when she came home from school, whenever her mother had gone into town. She also prepared meals for the family, and when her mother had "a bad headache and had to be in bed," she put cold packs on her head to ease the pain.

She learned to bake pies and cakes by the age of 9, and her mother was very pleased with her and bragged about this to all their family. This gave Ellen more motivation and confidence and she enjoyed this chore. When she was

10 years old, her mother gave her a magazine with recipes and stories of a mother and daughter cooking and baking together which has inspired her to this day.

Living on a farm meant caring for chickens, pigs, and cattle. Herding cattle along the roadside where there was lush green grass and sweet clover and bringing the cows home in the evening was part of her chores. In addition, she and her sister milked cows and fed calves and pigs. She gathered eggs and prepared them for her mother to take to the market. Keeping her room clean and washing dishes were also part of her daily chores.

When she entered high school, her goal was to become the valedictorian of her class because her sister had won this honor 2 years before. She accomplished this goal and was given a scholarship to attend college. However, she did not accept it. She decided to become a bookkeeper or a stenographer, so she attended Commercial College in Great Falls.

While attending Commercial College, Ellen worked for her room and board. Her responsibilities included getting up early and making breakfast for about 20 boarders before she went to school each day. She attended school until noon, at which time she went back to the boarding house, ate lunch, and helped with the dishes. She then attended school in the afternoon and in the evening she helped with the meal and with the dishes before she did her studies.

After graduating from Commercial College, she worked as a bookkeeper for a large company in Seattle, Washington for 3 years during World War II. There she met Edward who was stationed in the Coast Guard near Seattle. They were married during the war.

When the war ended, she and Edward returned to Great Falls. He was formerly from Montana and got his job back with the Great Northern Railroad. After 3 months on the job, another decision had to be made, as his parents were retiring from their farm. Ellen and Edward were given the option of taking over the farm and eventually buying it or staying with the railroad. They both made the decision to live on the farm, which turned out to be the right decision for them. They worked hard together and enjoyed the country life for many years.

Other decisions that were made following the buying of the farm were the purchasing of farm equipment and building their own home. They designed the plans for their home and actually did most of the work of completing it themselves.

Summary

Some of the important learning factors that influenced decision making for Ellen were the examples set by her mother. When her mother was left alone to raise the family, Ellen learned that determination and working together were very valuable. The family, due to their life

circumstances, were forced to make numerous decisions in order to survive. By constantly drawing upon previous good experiences and decisions, they transferred the learning from one situation to another for their benefit.

Early heavy responsibilities as a child enabled Ellen to learn how to make decisions. She was presented every day with problems and situations that demanded decisions on the farm.

Her mother remarried when Ellen was in Seattle, and Ellen reported that she had learned much about generosity from her stepfather. He was a kind and giving person who trusted her and this increased her self-esteem and self-confidence. These two qualities, self-esteem and self-confidence, helped create the basis for Ellen to later make good decisions, especially in times of great stress.

Listening to adults talk when she was a child was listed as a learning aid. She watched, listened, and learned from the adults in her life. These persons were primarily her mother and her grandparents, who demonstrated the ability to overcome many difficulties by making good, wise, and timely decisions, and these served as models for Ellen to follow.

Finally, after Ellen married, she and her husband made all their decisions together. Their combined life experiences, along with their decision making history, enabled them to share these strengths for making good

decisions during the great emotional stress of hospice care for Edward.

Case Study 6--Mary

Interview Dates: August 31, 1994 and November 30, 1994.

The caregiver in this case study was Mary, 68 years old, who cared for her husband, Alvin, who was 71. The first part of the case study examined the care and decisions made for the hospice client and the second part focused on the history and the learning experiences of the caregiver which had an impact on her decision making.

Alvin suffered from cancer of the liver, which had originated in the prostate gland and metastasized to the liver. An initial biopsy was done when he complained of a pain in his side, and at first the results did not show cancer, but later tests confirmed that it was. Several different types of chemotherapy were tried. The first type did not help, so others were used. In all, three types were used, and Alvin continued to take chemotherapy for the last 10 months of his life. He had many adverse effects from the therapy and at times wanted to quit, but Mary said, "he was grasping for extended life and went ahead with the treatments."

Alvin's doctor never told him or his family that his illness was terminal. At one point, Alvin became very ill from a gallbladder attack, so the doctor admitted him to

the hospital and surgically removed his gallbladder filled with numerous stones. From there he was discharged to his home, where Mary had made arrangements for hospice care. Hospice ordered a hospital bed and set it up, and a morphine pump for pain was placed in the home along with all the necessary supplies and dressings.

Mary heard about hospice through a Home Extension Club of which she was a member. One of the nurses from hospice had spoken to the group and had left literature describing the services they provided. She also had heard about hospice from a man who attended her church and who formerly had used hospice for his wife who was terminally ill with cancer.

Some of the good points about hospice that were mentioned by Mary were,

The nurse was here and left an information manual with all the necessary phone numbers. We shared the literature with our daughter and son and they agreed that we should use the service. The nurse came out every other day to begin and regulate the morphine pump and would change it from one place to another on his stomach. She helped him into and out of the bathroom and checked his vital signs. She also suggested that we have a 'Do Not Resuscitate' order from the doctor, in case we needed to call an emergency crew. He had an irregular heart beat and that worried us, but all in all I can't say enough good things about hospice.

The only bad point mentioned concerned an incident when her husband fell from his cot in the TV room. Mary had also been sleeping in the room and was unable to get

him back in bed because he was dead weight. She called hospice and they came out immediately and lifted him to his bed. Mary said, "My only suggestion was that we could have used a hospital bed sooner to keep Alvin from falling out of bed."

The family's preference was to have hospice because Alvin had said he wanted to die at home. With hospice coming to check vital signs, he felt comfortable and did not want to go back to the hospital. "I gave him my promise," Mary told the hospice nurse when she had asked, "Are you really sure you can go through with this"? Mary had further replied, "I don't know, but I want to do what he wants and what the children want."

The family had a son in Bozeman and a daughter who lived across the street from them. The son called every day for 2 months before his father died. The daughter visited every day and during one visit Alvin told her that he did not want to go back to the hospital, but wanted to die at home. The daughter moved in with her parents the last 2 days and helped with his care. Alvin had been ill for 3 years, but had hospice care only 1 month before he died at the age of 74.

Some of the skills that the family already possessed were cooking, cleaning, shopping, and some nursing skills. The nursing skills had been learned when Mary's mother was in a nursing home with Alzheimer's Disease and later when

Mary was her sole caregiver during the last 3 years of her life.

The beliefs expressed by Mary were,

We can't avoid death, it happens to everyone. We are of the Baptist faith, and we believe that the soul lives on and goes on to the Lord and everlasting life. We may fear it a little, but we hope to remember the teachings of the Bible when the time comes. We've conquered death by Jesus dying on the cross.

Their physical needs were met when hospice sent personnel into the home and when they were able to call for help anytime of the day or night. Mental and emotional needs were met by having Alvin at home and when the nurses came in to check on him and kept his medications at an adequate rate to relieve pain. Mary said that the social worker who visited once a week was a great help in preparing paperwork and filing claims with Medicare and the insurance company. In addition, the volunteers were very helpful when they delivered supplies and medications to their door and when they sat with Alvin occasionally and gave Mary respite. Their own pastor filled the role of providing for their spiritual needs when he prayed with them and brought the Last Supper to Alvin.

Others who helped with Alvin's care were their neighbors and friends and some of their friends from church. A volunteer came in and helped with housework so the 24-hour caregiver could occasionally take a nap. Friends and neighbors took turns going to the store and sat

with Alvin at different times. His lodge brother came over to visit, which Alvin greatly enjoyed.

Alvin was capable of making the decision to have hospice, and together with Mary they made the decision. Their doctor made the arrangements for them. Alvin was determined not to go back into the hospital or have numerous injections for pain. His other reasons related to finances and the environment of the hospital versus his home. Alvin had Medicare and a supplemental insurance policy which paid some of the bills, but Mary reported that the doctor paid 20% out of his own pocket for the gallbladder surgery. It had cost \$15,000, and was not totally covered by their insurance.

When asked about decision making, Mary said, "No, we were not really prepared, but we knew what was best for Alvin and what he wanted, and by hanging in there we just did it." However, as she stated,

I had a rather strong personality. I think it was a good thing, since I was married to a military man, and when he was gone I was left alone with the two children. We moved many times, and lived in many places away from my family, so perhaps it was good discipline for us. I kept the kids at home, and other kids came to our house. When my husband was gone hunting, I was forced to make the decisions. My husband was a lousy manager, so I had to take over paying the bills.

One of the hardest decisions Mary and Alvin had to make occurred when he retired from the military in Montana. They owned a house in California and really wanted to go

back there to live. While at an air base in California for a physical checkup for Alvin, they looked at the home again and decided that the house in Montana was the better of the two. Other factors they took into consideration were the children who were in the Montana school system and wanted to graduate with their friends. Further, Mary had a good job as a secretary for a construction company and Alvin had a job with the Fire Department, so together they decided to retire in Montana.

No blocks or hindrances to decision making were experienced by Mary and Alvin during the time of hospice that were not solved by either the hospice personnel or their brochures. Mary reported, "They were wonderful to us and answered many questions for us. It was the best thing for us at the time."

In order to determine how prior learning experiences affected her decision making during great emotional stress, Mary's history was explored. She was born in Mondovi, Washington, in 1926, as a middle child with an older sister and a younger brother. She grew up on a farm, and she recalled that at the age of 6 she had regular daily chores. She gathered eggs, fed the chickens, and stayed with 40 to 50 head of sheep, often in the field a half day at a time. She had a sheep dog who helped her with this chore.

Between the ages of 8 to 9 years, she had additional chores. She still helped with the sheep, fed lambs with a

bottle and nipple, and helped her mother raise turkeys. Sometimes she did not do her chores, and, as Mary said, "I got a good spanking." At age 9 she was "bossy," telling her brother and sister what to do so they would have time to play. Her mother told her she was too bossy and told her to stop this behavior and mind her own business.

In the summer, Mary worked in the garden where she pulled weeds and picked produce for meals. At the age of 10, she helped care for pigs, lambs, chickens, and cows, and milked five to six cows a day in the morning and evening. She washed dishes and cleaned "the awful milk cans and cream separator." She hated that job.

After the chores were finished, she studied for school.

She attended school in a one-room schoolhouse located a mile from her home through the sixth grade. There was one teacher who taught all the grades from the first to the sixth grades. The school had a different teacher every year. All the teachers roomed and boarded with a family nearby until the last teacher, who lived with Mary's family. Most of the students at the school were Mary's own cousins.

After the sixth grade, the school closed and the students from the area were bussed to another town 18 miles away. Mary reported that at the age of 12, she was "good sized" and her mother relied on her to help with more of the cooking, cleaning, and the laundry. The family always

had two hired hands who worked on the farm and lived with them in the home.

At the age of 14, Mary was "pretty grown up" and quite mature for her age. She knew what chores she had to do and did them without being told. She said her mother did not let her make any major decisions at this time, but she felt like she wanted to. She was not allowed to go to the high school dance, but did go to the senior prom with a neighbor boy. Mary wanted to belong, and to be a team player, but was not allowed to most of the time.

Mary's older sister was mildly autistic, or as Mary said, "rather simple." Her mother favored her sister, which caused Mary to think that, "My mother was always mad at me, not at my sister. She favored her because of her disability. My sister didn't have to ride out with water for the hired hands or take care of the chickens or anything."

After high school, Mary attended a business college in Spokane and took courses to become a secretary. While attending school, she lived at a doctor's home and worked for her room and board. When she graduated she worked 2 years before she married.

At the age of 18, Mary married a man in the military service. They had two children and they moved a great many times in the Air Force. Because her husband was away much

of the time, she had greater responsibility for all the decisions that attended child rearing.

When Mary was 24 years old, her father contracted cancer and was in failing health after 3 years of treatments. At this time, Mary and Alvin were living in Kansas City, and Mary came back to Montana to help care for her father. Her brother took over the family farm and did well, but Mary said, "Mom and Dad argued a lot; nothing my brother did was right. They were used to running the farm their way, and that's how they wanted my brother to run it."

When her father died, Mary's mother continued to rely on her, but she never got the love or recognition that she felt her sister received. Her mother helped her sister in many ways, especially after her father died, and even took trips with her. Her sister worked as a clerk in a dry goods store a total of 44 years and was able to care for herself but was unable, Mary said, to help others.

In 1980, her brother was killed in a car accident and her mother's health started to deteriorate. During her grieving, her mother started visiting her neighbors and asking about insurance papers. Other occurrences included shoveling snow in the winter without a coat and frequent forgetfulness about her activities of daily living. Mary stated that it was then her mother was diagnosed as having

Alzheimer's Disease and was placed in a nursing home for 2 1/2 years.

She was very unhappy in the nursing home, so Mary took her mother into her own home and cared for her for 3 years. During this time, she said her mother did not know anyone or anything and it was a "living hell" for her and her family. After her mother died, Mary took her home and buried her. She said, "My sister was not involved at all and did not help with the funeral because she never did learn responsibility."

Summary

Some of the life experiences that led Mary to learn how to make good decisions were the many responsibilities that she accepted from the age of 6 years on. Care of the house and the farm animals required daily decisions by Mary, and especially when she worked in the fields with the sheep. At this time, she had no adult supervision but had just herself and her dog to rely on. Much of the work she did was strenuous for a small child.

Since her sister was afflicted with what now would be considered autism and was unable to do her homework alone, Mary helped her all the days of her schooling. Mary said she did not mind helping her sister, but it did take time away from her own studies, and she felt she could have done better in school if she had only her own work to do.

One winter her father's sister, a Jehovah's Witness, stayed with them. Her aunt possessed great faith, taught her how to pray, and talked with the family about the Bible. She also "had wit about her" and the family greatly enjoyed her company. Mary stated that her aunt had greatly influenced her by her religious beliefs.

Other factors that influenced Mary were listening to the members of her family and watching them from the upstairs balcony when she was supposed to be asleep at night. Further, the examples of sharing by her mother and father were important. They gave food to others who stopped by their home, and at Christmas time they gave nuts, candy, and oranges in paper sacks to their cousins. The learning of generosity and caring for others helped her later when her husband was ill.

Marriage to her husband was considered instrumental to Mary's learning how to make decisions. In the course of their marriage, she assumed the responsibility for the checkbook and for paying the bills. In his work, he was away from home a great deal, and she was forced to make whatever decisions needed to be made for herself and the children at the time. These experiences developed a basis of strength, courage, and know-how that were very valuable to Mary when decisions needed to be made during the emotionally stressful times of hospice care for her husband.

Case Study 7--Blanche

Interview Dates: August 28, 1994 and December 2, 1994.

At the age of 68, Blanche was the caregiver for her mother, Mildred, 88 years old, who had been diagnosed with lung cancer. The first part of the case study examined the caregiver and the decisions that were made during hospice care. The second part of the case study explored the life history and experiences of the caregiver which were relevant to her decision making during the emotionally stressful conditions of hospice.

Mildred learned that her disease was terminal in 1993. Her doctor was very supportive and told her, "As long as you have a living will, I will just keep you comfortable." Altogether, she was on hospice for 8 months. A volunteer prepared her breakfast every day, a social worker visited quite often, and the nurses also checked on Blanche frequently to see if she was doing all right. Blanche had a power of attorney to care for her mother's medical care and was instrumental in having a will written for her.

Blanche reported that the good points about hospice were many, because the nurses made it possible for her mother to stay at home until 10 days before she died. They came to the home at least two times a week to take her mother's vital signs and to make sure the pain medication

was adequate. No bad points or suggestions were offered by Blanche.

Mildred was a very independent person and preferred to remain in her own home and wanted to die at home. Although she was diagnosed by her doctor as having cancer, she believed it was tuberculosis and refused to admit it was cancer. The only treatment she accepted was pain medications for her arthritis. She was frequently angry with her daughter because she wanted her to stay with her all the time, but this was not possible because Blanche had to go to work every day.

During her last 2 weeks at home, Mildred became disoriented, fell, and was very badly bruised. She was admitted to the hospital for treatment and was transferred from there to a nursing home for the last 10 days of her life.

Long before Mildred became so ill, Blanche had promised her that she would never place her in a nursing home, but the time came when she was unmanageable at home and needed 24-hour care in the nursing home. "I promised her what would happen and I couldn't keep my promise. What she wanted was to stay home and die. She should have been able to do that."

Blanche said she suffered from guilt feelings, but she said, "When Mama went into the nursing home it was a blessing and a relief to me. I couldn't stay home and do

24-hour care for her. As it was, I helped with her care from 9:00 p.m. to 9:00 a.m., and then went to work in the morning." Blanche was a diabetic and worked to supplement her small Social Security income and to provide the extra supplies needed for the diabetes. At this time, she had worked at Head Start for 5 years and as a teacher's helper for 3 years at the Longfellow Elementary School.

The family had some prior knowledge of hospice because they had used its services for Blanche's brother 5 years before, but they did not remember all the services it had offered. Since Mildred was a very private person, she did not like "a lot of strange people coming in and out of my home." However, she did accept help with the breakfast meal, with a noon meal brought to the home by Meals on Wheels, and by the various support people from hospice who helped with bathing, shopping for foods, and with medications.

At first, Mildred was content to be alone during part of the day, but later she made numerous daily calls to Blanche's place of work to check on her. This was an irritating and difficult situation for Blanche and one for which she found no solution.

Many others outside the family helped during hospice care, especially one friend, Laura, who came in on Thursdays and gave Mildred a bath and shampoo. The

alternative, according to Blanche, would have been to place her mother in a nursing home much earlier.

The family's physical needs were met when hospice sent workers into the home to care for Mildred and the home. The mental and emotional needs were met by the nurses who kept in touch with the doctor and got answers to their questions. This provided peace of mind for the family. For their spiritual needs, they relied on their own pastor from the Baptist church.

When asked if the family was prepared to make the difficult decisions at this time, Blanche replied that they were. She said that the nurse from hospice and the doctor both explained the program very well. In addition, she said that of all the things that helped, prayer and her life experiences were the most help.

These life experiences included managing a funeral home for 2 1/2 years. Later she had worked for several years with her husband, who was a mortician, before he retired. When he died, she was in charge of the service for his funeral. Working in a funeral home had given her a different perspective about death, and she dealt with it in a relatively calm manner.

According to Blanche, both she and her mother were Christians, who had received the Lord as their personal Savior and were looking forward to going to heaven when they died. During the later stages in the illness when

Mildred was bouncing up and down in her bed and fighting the nursing home personnel, Blanche had said to her, "Mama, let go and let God take you home to see Dad." She said her mother calmed down and seemed to be more at peace after that.

Blanche's methodology for making decisions was "first to consider all options, and pray about it because the Lord gives us scriptures to back up the decisions we are supposed to make." Her mother made her own decisions and even made the final decision to have hospice care. The key to making that decision was being able to stay at home during most of her illness. Medicare and a supplemental policy paid for the services for her care.

Blanche reported that she did not experience any blocks when making decisions until it came time for her to retire. She said that she liked to work and wanted to work past the age of 62. She wanted to stay in the mainstream of life. She enjoyed working with children and getting out of the house. She said she felt a "little guilty because she couldn't be the 24-hour caregiver for her mother," but she was not emotionally or physically able to do this. Moreover, she needed to work to support herself.

In order to more fully understand how lifelong learning has benefitted her decision making, an examination of Blanche's history is warranted. She was born May 28, 1922, in Calgary, Canada, and at that time her parents

lived on a farm. Her father worked on the Great Northern Railroad and her grandmother lived with the family. However, after Blanche was born her family moved to Whitefish, Montana, where they lived in town. Her father's work required that they move often, so she completed her first eight grades in four different schools: Whitefish, Troy, Newport, and Shelby, Montana. This required Blanche to adjust to fit in at each new school and to make new friends.

At the age of 7 she had a room of her own and her main chore was to keep her room clean. She walked seven blocks to school and went home for lunch everyday. She recalled that the snow in winter was often higher than her head and the winters were bitter. Since the schools were small, they had one teacher in grades 1 through 8, the same as they had in the country schools. She liked everything about school, except mathematics, which she did not understand.

When she was 12 years old, her mother became ill and Blanche took care of her baby brother. This was the most responsibility she had been given so far, and she reported that she felt quite grown up and made many good decisions for his care during this time. The baby did well under her care.

She credited her grandmother with having the greatest influence on her learning to make decisions. Blanche explained,

In addition to buying roller skates and a bicycle for me, she brought extra good feelings into our home and taught me a lot of things. She was always honest, loving, and kind. She read the Bible every night before bedtime. She even made a white flannel nightgown for me which was just like hers. She called me her little teddy bear, and I got along well with her.

Blanche was a member of the Honor Club her senior year in high school. She was active in school meetings, had bit parts in operettas, and one time had the honor of traveling to Kalispell to sing on the radio. She also helped with the production of school plays and sang for residents at a local nursing home. A large part of her life centered at the Presbyterian church where she worked for the pastor in the church office and sang solos for the services. While she lived at home from the 9th to the 12th grades her main responsibilities were doing dishes, keeping her room clean, and doing her studies.

When the family lived in Shelby, her grandmother bought a lot on Whitefish Lake and built a cabin. Blanche and her brother often rode the train to Whitefish and spent entire summers with their grandmother and uncle. This was an extraordinarily good time for Blanche and she loved the freedom of the lake atmosphere.

After graduation from high school, Blanche's aunt offered to pay for college at Santa Barbara State in California. Blanche attended college for only 6 months. She said,

I was a small town girl in a big city where it rained all the time. In my spare time, I worked in the tomato fields, drank tomato juice, and ate tomato sandwiches. I became very homesick and went back home, where I worked in a local drug store. I was happier there.

Her boyfriend was in the National Guard and was drafted into the Army. Blanche was 18 years old when she met him in Seattle and they married. They were transferred to several bases while he was in the service and their two daughters were born during that time.

After the war her husband was discharged and worked as an apprentice at a funeral home in Seattle. Later, he attended a mortuary college in Tacoma and became a mortician. When he graduated, they moved to Cut Bank, Montana, where Blanche helped manage a funeral home and where their two sons were born. Several years later they built their own funeral home and worked there for many years, leasing it to others when her husband retired.

Summary

The main factors in Blanche's life which proved instrumental for good decision making included the examples of her parents and her grandmother. She learned how to make minor decisions as a child by listening and learning

from her parents' example. Caring for her baby brother when her mother was ill was an important time of learning and accepting responsibility. She said that her parents usually discussed everything together and she had never heard her parents fight or argue in her presence. They usually worked together toward a mutual agreement.

Her grandmother was another very important person in her life and taught Blanche many basic values, such as honesty, kindness, love, faith in God, and generosity. Her grandmother had more patience and more time to spend with Blanche and appeared to understand her better when she was a child than her mother did. To this day, when she has important decisions to make, she thinks about her grandmother and tries to remember what she would do in a similar situation.

The schoolteachers that Blanche learned from were also mentioned as being models for learning how to decide issues. Blanche stated that all her teachers set a good example for her to follow, and she is thankful for their influence in her life.

The marriage to her husband, she said, was "not a real happy marriage," because Blanche said, "I had to do it all." However, she did admit that having to do it all taught her to be independent and gave her a strength which later enabled her to rise to the occasion when difficult decisions needed to be made. In addition, her experience

of working with him in the funeral business was certainly helpful when she had to deal with his death, as well as her mother's death.

And finally, Blanche said, "My good childhood, when I was very happy, was what formed the patterns of my life that have sustained me in my recent time of sorrow and decision making for mother. It gave me a solid base to work from and I am grateful for that."

Case Study 8--Jean

Interview Dates: August 31, 1994 and February 3, 1995.

Jean, 68 years old, was the hospice caregiver for her husband, Gary, who was 69. He suffered from colon cancer which had spread to his lungs. The first part of the case study addresses the various aspects of decision making during hospice care. The second part of the case study focuses on the personal history and life experiences of the caregiver and how those factors related to the caregiver's ability to make decisions during great emotional stress.

After Gary's first diagnosis and surgery in 1984 in Washington, D.C., he had a number of chemotherapy treatments. However, in 1986 more surgery was required and a colostomy was performed which stabilized him for several years. He learned that his condition was terminal in March 1993. The total length of his illness was approximately 10 years.

When Jean asked his doctor if he was going to do more surgery, his doctor replied, "No, keep him at home and make him as comfortable as possible." Jean had heard about hospice before from some friends, but thought it was a hospital where people went to die. Gary was referred to hospice for care and one of the nurses went to the home and talked to them. She explained the program, gave them all the information they asked for, and left literature for them to read.

Prior knowledge regarding hospice was gained when Jean lived in the Washington, D.C. area. A friend of theirs, a nurse in Louisville, Kentucky, had used hospice for her husband for 1 year before he died. Some of the things her friend had told her affirmed that hospice was a good service. Her friend had been able to continue working, and the services that hospice provided were comforting.

Although finances were not a great problem for them, they did have Medicare and supplemental insurance which paid most of the bills for hospice. Jean had only good comments to share regarding the care her husband received and the help she was given.

When Gary was having breathing problems, the nurses came to the home every day, measured his vital signs, and helped with his ambulation. At first, he could walk by himself, but later he needed a great deal of assistance. No adverse comments regarding hospice were made by Jean.

During the last few weeks of Gary's illness, Jean also was ill and had to be admitted to the hospital for a mitral valve repair on her heart. She returned home shortly thereafter and her husband died a few days later. While she was in the hospital, Jean said, "There was no question in my mind he would still be there at home when I got back." During her absence, Gary was cared for 24 hours a day by a local home health care agency employed by the family.

There were no children in the family, but Gary had a brother who was suffering from a heart condition caused by a blood clot in the aorta. Gary had made arrangements for his aorta to be donated to his brother when he died. When asked how she felt about that, Jean said, "It was comforting and it was my husband's will. He was well prepared for it, as it was the act of giving the gift of himself."

Some of the skills Jean had previously learned that were useful during Gary's illness were cooking, cleaning, and shopping. He was on a special diet that his doctor ordered and Jean prepared the diet for him every day.

Gary had a strong faith in God and said that he was not afraid to die. He said, "I have enjoyed my life. I'm not in any hurry to go, but I will go whenever it's my time." He wanted to have everything in order before he died, and made sure this was done. He did not talk about

his spiritual beliefs and he did not attend church, but Jean said he really lived his faith. "The day he died he accepted Christ," she said.

The family's physical needs were met by the nurses and other hospice personnel when they came into the home several times a week and helped with Gary's personal care. Their mental and emotional needs were met when they used hospice because it reduced the pressure they felt and relieved their minds to have others with whom to share their burden. Jean reported that they looked forward to the days people came from hospice. Their spiritual needs were met by the hospice chaplain who visited them at home.

In addition to the home health care agency which was in the home 24 hours a day, others who helped Gary in the last days of his illness were a brother, his wife and their children, and their neighbors. In lieu of this help, Jean's only other alternatives would have been to place him in a nursing home or a hospital or to hire a live-in person.

When asked if she and her husband were prepared to make the decisions necessary for hospice care, she replied,

Yes, and I relied heavily on my husband. We would discuss things, consider the pros and cons, and consider all the options before deciding. In some cases, however, we didn't have much of a choice. We had to do what we had to do. One's conscience plays a part, and I had to do what I could live with later.

Regarding the decision to accept hospice care, Gary was able and did help make the decision with Jean. When the nurse from hospice came to their home and explained the services they provided, they felt confident it was the best way to go. Gary had reached the point of disability and Jean was unable to care for him alone. The one factor, though, that was the deciding point for hospice was his ability to remain at home in his own environment. Jean said that his being near his family members and being able to die at home were the only reasons she and Gary had moved to this area from West Virginia.

The life history of Jean and her experiences revealed numerous occasions in which she learned decision making. She was born in Cooperstown, North Dakota, in 1925, and some of her earliest memories were from the time she was 4 years old. Her family lived in town and she had made friends with a little girl who lived nearby. This little girl had a beautiful doll which was kept in a box. When the lid of the box was taken off, Jean said that the doll looked so real that her first impression was that it was a dead baby in a casket. She did not recall why she thought that because she had never seen a dead person before.

At the age of 6, Jean attended first grade at a public school in the little town of Shama, North Dakota (now gone). The next year the family moved to a place where she attended a country school. All classes from grades 2 to 5

had one teacher. She said she loved school right from the start.

Although the family was extremely poor and life was not easy, she said no one picked on them because they did not have any money. Clothes were mostly hand-me-downs when she was a child.

The family moved to Beach, North Dakota, when Jean was 11 years old and at this time her younger brother was born. Jean had wanted a sister badly, and when her mother told her she was pregnant, Jean was very frightened because she had heard stories about how "ladies die when they have babies." The night her little brother was born, her two older brothers were gone. Before her father took her mother to the midwife, her mother had told her, "You can sleep in my bed tonight if you will feel better," so she did. Later, when her father came home and said, "You have another brother," Jean did not believe him until she saw the baby for herself. She explained that sometimes her father teased her.

Since Jean had been the baby of the family for some time, and since she had wanted a baby sister but instead got a baby brother, her father fixed her doll crib for the baby and used one of her doll's bonnets to bring him home. This made her feel a little better toward the baby.

Several decisions that Jean recalled making when she was 11 years old involved some baking chores. She decided

to make bread from a "starter" batter her mother kept in the kitchen. It turned out like a brick, so hard no one could eat it, and she was teased about it for a long time. Another time, she said, "I made cookies, put them in the oven of our wood range and got the fire going good. Shortly afterwards, one of my brothers opened the oven to look at the cookies and said, "Jean, your cookies are boiling; I think the batter was too thin." And finally, one day she made a cake, banked the fire, walked into town to see her mother on a cold December day, and when she came home she found a warm, soggy mess in the oven. In spite of the fact that these attempts at adult chores were minor disasters, Jean said she was not unduly discouraged but decided to practice more and later was able to bake very well.

At the age of 12, she went to school in a nearby city. She told how this was a shock to her, because all the students were in the same grade. It was very scary for this country girl to make the transition to city schools. Her younger brother attended the same school and was later seen to be the most learned person in her family. Jean explained that her brother skipped two grades and took the seventh and eighth grades with her. They took part in spelling bees and mathematic bees during those years and won nearly all of them. She was very proud of her brother, looked up to him, and always wanted the best for him.

During her high school years, Jean worked after school for the National Recovery Act agency, correcting papers for teachers. She decided to earn enough money to pay her and her brother's office account for books and supplies. Her younger brother was the valedictorian of his class at the age of 15, breaking all previous school records.

The year she graduated Jean's father moved to the West Coast to work in construction. Her younger brother went into the Army in 1942. Her older brother worked in town until she graduated from high school. Jean was extremely frightened of big cities and of going out into the world on her own, so she decided to move to Richey, Montana, and live with her mother's two sisters. Her mother and her brother went by train to Tacoma to be with her father, but Jean did not go with them. Instead, she stayed in Richey and worked at a bank. She lived with her aunt and uncle, and did housework in exchange for her room and board.

In 1944, she and a good friend from Richey moved to Great Falls and found a job at Farmer's Union State office. After about a year, her brother came home on furlough to Great Falls and when he returned to his military base she went with him to Washington State and worked as a Nurse Aide in a hospital for over a year.

After the war ended, a friend from Richey decided to go to Camp Lee, Virginia, to see her boyfriend in the service and Jean went with her. Her father was heartbroken

on hearing the news and cried when he found that she was going to move so far away from home. Jean explained, "I was always Mama's baby, and I didn't realize what a great guy Dad was until I was grown up and away from home."

Jean worked in Virginia for a storage company as a secretary and all-around Girl Friday for 8 years. She met her husband-to-be there. After they were married, she worked for the government at the Department of Agriculture for 30 years and retired in 1984. Her husband worked for 31 years as the chief financial officer for a large hospital with 2,000 employees and retired the same year.

Summary

The learning factors that Jean considered important for her to make good decisions were her parents who taught her right from wrong. Her parents said they trusted her to make good decisions, and out of respect and love for them she always tried to do so, to keep from hurting them in any way.

The responsibilities she had when she was just a child were also helpful to her because they gave her many chances to practice making decisions. This way she discovered what worked and what did not.

Her faith in God was also an important factor because she said she always prayed for a sign or a feeling which

guided her when she had important decisions to make and it never failed.

Her husband was very supportive and encouraged her to discuss issues with him before making final decisions. She said they always "reasoned together." They weighed one thing against another and came to a final solution that their decision could be based upon. Gary was a planner by nature, always paid cash, and wanted everything in order and done in advance. The many years Jean worked for the government provided many opportunities for her to use her decision making skills on the job.

Jean confided, "Before hospice care, I had a tendency to put off making decisions if I had the time, but when we were working with hospice, I learned how to make decisions more quickly because the need was great and I didn't have much choice."

Summary of the Interviews

The first interview was conducted using 11 primary questions. (See Appendix A for these interview questions.) The interview questions were reviewed by 5 hospice experts who served as practice interviewees before the actual interviews were conducted with the caregivers. (See Appendix B for the names of these hospice experts.) The length of the interviews varied from 2 to 2 1/2 hours.

During the second interview, the participants were asked to tell their life story with a focus especially on their learning, their responsibilities, and their experiences, beginning with their earliest memories. The length of the interviews was from 1 1/2 to 2 hours.

CHAPTER 5

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

Summary of Findings

This study examined lifelong learning and its influence on decision making by individuals during the emotionally stressful situation of hospice care. Each of the 8 individuals who participated in the study was interviewed twice. These volunteers were 4 men and 4 women who ranged in age from 52 to 85 years old, with an average age of 74. All had been the major caregiver for a loved one with terminal illness at some time during an 18 month period before the interviews. All interviews were done in the caregivers' homes.

All caregivers gave the hospice personnel high ratings for the information and care they supplied the families. When a family had reached the point where hospice care was a necessary component in being able to maintain the terminally ill person at home, hospice personnel made a big difference. They stepped in and provided answers to the question, "What do I do now?"

It was surprising how few of the families had prior knowledge of hospice care before using it. Three families

had never heard of hospice, while 3 others had heard of hospice but did not know what services they offered or who was eligible to use hospice. Only 2 of the 8 families were familiar with hospice, the services it offered, and the eligibility requirements.

Everything hospice provided was reported as good, with no complaints at all by 6 of the 8 families interviewed. The most commonly mentioned benefit was the ability of the dying person to stay in their own home environment. Other positive comments included noting the honesty, courtesy, and efficiency of the nurses, obtaining effective pain control for their loved one, and getting all their questions answered about the hospice care situation. Also mentioned was the benefit of knowing that hospice personnel could be contacted and would respond 24 hours a day and that hospice shared the responsibility and burden of the impending death of their loved one. Equipment for mobility and comfort and delivery of needed supplies were also considered great benefits by the families. Finally, the cost of the hospice care was a factor which concerned the families; however, all 8 of the families had Medicare and a supplemental insurance policy which paid all the bills.

Two families who were generally grateful for hospice did have suggestions to make. One would have appreciated receiving hospice at an earlier time in the illness in order to obtain better pain control for his loved one. The

other family suggested that having a hospital bed in the home earlier would have prevented a fall.

All 8 of the dying individuals in this study had told their family caregiver that they preferred to die at home. The alternatives considered included a hospice room in the hospital, which was considered by 7 primary caregivers; placing their loved one in a nursing home, considered by 4 families; hiring a live-in person to help, considered by 2 families; and one caregiver considered asking her daughter for more help while maintaining the dying person at home.

Formal education which the primary caregivers had received prior to caring for their loved one varied from completion of third grade to 14 years schooling with an associate degree. One participant had completed third grade, one had completed fifth grade, one finished the eighth grade, two had completed 12 years with high school graduation, one had 12 1/2 years schooling, which included 1/2 year college, one had completed 13 years, which included 1 year community college, and one individual had completed 14 years, graduating with an associate degree.

When asked how hospice care met the physical needs of the participants, all 8 replied that they needed help with the personal care of their loved one and needed the help of professional nurses to keep in contact with their doctors and to regulate and maintain pain control medications. The

delivery of equipment and supplies to the home was listed as very important by 2 of the participants.

Seven participants reported that hospice met their mental and emotional needs by relieving the pressure and providing them with peace of mind by being able to call on them 24 hours a day. Having the social worker to talk to and to discuss problems with was cited as important by 4 of the participants. Three of the caregivers said that sharing the responsibility of the loved one's death was an important emotional need that hospice met for them.

The spiritual needs of 6 of the caregivers were met by their own pastors, one called on the hospice chaplain for support, and another one handled his own spiritual needs.

The participants stated seven main reasons why they and their family accepted hospice care for their loved one. In order of importance they were home environment, relief from pain, the caregiver needed help and relief from "burn out," out of great necessity, it was considered best for the well-being of the loved one, convenience, and because of caregiver disability. See Table 1 for these factors.

The participants in the study reported 11 factors which they thought influenced their ability to make decisions. In order of frequency of mention they were early childhood responsibilities, life experiences, examples of their parents, weighing the pros and cons, considering all the options, a good marriage, common sense,

Table 1. Factors Which Determine How Caregivers Make Their Decisions.

Factor	No. Caregivers
Childhood Responsibility	8
Examples of others (parents)	8
Life Experiences	7
Weighing the Pros and Cons	6
Marriage	5
Considering Options	5
Prior Caregiving	4
Common Sense	4
Praying About It	4
Golden Rule	3
Talk to Others	3

prayed about it, prior caregiving experience, talking to others, and using the Golden Rule. See Table 2 for these factors.

Table 2. Reasons Caregivers Gave for Accepting Hospice Care.

Reason	No. Caregivers
Relief from Pain	8
Home Environment	8
Needed Help	6
Necessity	5
Best for Well-Being of Loved One	4
Convenience	3
Caregiver Disability	2

Blocks to decision making when making decisions during hospice care expressed by the caregivers are listed in order of frequency mentioned. They were being emotionally upset, the fear of losing a loved one, not much choice, frustration, guilt, lack of spousal support, the tendency to put off decisions, and lack of education. Two participants stated that no blocks were experienced. See Table 3 for these factors.

Table 3. Blocks Experienced by Caregivers When Making Decisions during Hospice Care.

Block	No. Caregivers
Emotional Upsets	7
Fear of Losing Loved One	5
Lack of education	3
No Choice	2
Tendency to Put Off Decisions	1
Lack of Spousal Support	1
Frustrations	1

All the caregivers who participated in this study were born prior to 1939. All, with the exception of one person, were born and reared in a rural area. They lived through the Great Depression, World Wars I and II, part of the Agricultural Age, the Industrial Age, and the beginning of the Age of Information. In fact, they have witnessed more

major changes in their lives during the past 52 to 80 years than have occurred in many centuries prior.

Conclusions

1. Hospice is not only of great benefit to caregivers facing decisions about care for a dying loved one but an excellent example of an informal adult education program.

Hospice provides a learning environment by giving the physical support that releases families to make easier decisions during this emotional time. At a certain point in their home death experience, all of the caregivers and family members were so emotionally stressed and physically exhausted that they welcomed hospice's help with open arms. They felt a great sense of relief when they discovered that there was an organization that would help them.

When a family member first accepted the caregiver responsibility their loved ones usually were able to do most of their own care, but as their diseases progressed their health deteriorated to the point where they needed to have all personal care done for them. It was at that time additional help was necessary and hospice was the answer to their needs. Hospice care was eagerly accepted by all of the caregivers and their loved ones when it was offered and explained.

In addition to needing the emotional support and physical help, the caregivers and family members indicated

that they wanted answers to their questions about the death and dying process. They wanted to know if there were others who would share in the responsibility and emotional stress of a home death. The acceptance of hospice home care provided not only a sense of relief, which greatly lessened the emotional upheaval for the caregiver, but it helped prevent "burn out" of the caregiver. Giving the caregivers respite occasionally was absolutely essential for maintaining their health and strength and enabled them to continue in the primary position of caring for the patient.

Knowing that there were others who could help by providing answers to questions as well as personal care help for the patients was very important. This made the goal of death at home possible. Having a specific goal is important in how well an adult learns, according to Rogers (1968). Having the goal for a home death motivated all the participants in the study to learn what they needed to know in order to accomplish this goal.

Overall, Peace Hospice of Montana received an outstanding report from its former hospice users who were participants in this study. Their most commonly mentioned comment was the fact that their loved one was able to remain at home in the final days of life. Next in importance to the families was the ability to contact a hospice nurse any hour of the day or night and get a

response if the caregiver needed to talk with someone or if an increase in pain medication was warranted. Help with personal care of the terminally ill patients and help with household chores and shopping were considered as very beneficial. These services were provided by the hospice aides and the volunteers. The social worker was appreciated by the families for helping them fill out their Medicare and supplemental insurance forms, as well as being there when needed to solve personal, social, or financial problems of any kind. The social worker was also instrumental in listening to the caregivers and telling them that what they were doing was very worthwhile. Sometimes the caregiver demanded more time from the hospice workers than the patient did because they would become depressed and tired and lose confidence in their abilities to cope with the situation.

Hospice responds to the expressed needs of people as well as needs the hospice workers know will arise. It brings the knowledge and skills to the people when they need it. The support and information given by hospice helps build the self-confidence needed by care givers-- especially since it is available 24 hours a day. These factors indicate what it is about hospice that makes learning and decision making easy. "Hospice gave me all the information I needed."

2. For those terminally ill individuals who desire a home death, hospice home care provides the ideal support for families to realize this goal.

Although most of the families in this study had some experience with death, none had experienced a home death. Some of the caregivers had an unrealistic and fearful attitude toward death and dying. Herman Feifel (1977) wrote that many people of today view death as a mystery. These hospice families were no different, insofar as they had not visualized what a home death might be. This was one area where the hospice nurse was really able to help the caregiver, the family members, and the patient. After determining the stability of the family situation, the nurse gradually shared some of the facts of the signs and symptoms of impending death. She also encouraged them to share some of their views and what they thought death would be like. This open sharing of ideas and opinions helped demystify death for the patients and the families and greatly lessened their fears.

In addition, just knowing that they could call on the nurse to be with them at the time of the patient's death was extremely reassuring for the caregivers. Being alone with a loved one when he/she is dying produces feelings of great emotional stress, powerlessness, and sorrow. The feeling of being overwhelmed and the feeling of powerlessness was common among the hospice families. The

feeling of powerlessness did not arise because the patient was going to die but because they did not know when the death would occur. Stuhler-Schlag (1985) also noted this phenomenon in her study of hospice patients. Knowing that someone who has had experience with the dying process is standing by was one of the most helpful measures hospice provided the caregivers and the families.

The forewarning about possible symptoms and preparation of the caregivers for the impending death of their loved one were also determined to be important by Stuhler-Schlag (1985) and were identified by Gold (1983) as being important factors which enabled caregivers to cope with the death event.

The most common cause of death for those individuals using hospice was cancer. This debilitating disease often lasts for months and years and requires herculean strength of those who deal with it in the last few months. It is fitting that an organization such as hospice home care has come into being because the need for it has been present for decades. However, it was surprising to learn that three-fourths of the participants and their families had either never heard of hospice or had heard of hospice but did not know anything about it before using the service.

3. Childhood responsibilities and life experiences promote the ability for adult individuals to make emotional

decisions easier.

All of the participants responded that they had many responsibilities as children from the age of 6 years. Seven of the 8 participants lived their entire childhood in a rural area and only one person lived in town as a small child. The participants were children during the first half of the 1900s. Due to their families' financial circumstances and the many chores that farming demands, it was necessary that the children be given responsibilities at an early age to insure the survival of the family.

These life experiences provided many occasions by which the children learned to make decisions. All the participants shared their many experiences of hard work, responsibilities, and hardships during which they had endured both emotional and physical stress. This created a reservoir of self-confidence and common sense. Therefore, when they became adults and were called upon to make decisions that were of an emotionally stressful nature, they were able to draw on their past knowledge and experiences and decision making was easier for them.

This reflects the theory of Carl Rogers (1969) regarding the transference of past learning to a present situation when he proposed that the concept of self is formed as a result of the interaction of an individual with others and with his environment. As experiences occur in the life of the individual, they are organized into some

relationship to the self or ignored if there is no relationship. Most of the ways of behaving which are adopted by an individual are those which are consistent with the concept of self.

White (1988) also reported that prior experience is crucial in decision making. For example, when making judgments regarding the likelihood of success and the relative weights of the pros and cons of the issue at hand, an individual draws on his past experiences. In familiar situations there are a group of relevant episodes in the memory that can be drawn upon and decisions are based on these earlier situations and experiences. In an unfamiliar situation an individual may seek parallels between it and familiar ones. If a parallel is found, decisions can be based upon the earlier experiences, but if not found, outside help will be needed.

Thorndike (1968) also proposed that situations or experiences which an individual encounters form a basis for connections which can be useful at a later time for decision making. These connections are tendencies to call forth some particular response as a result of a certain stimulus due to prior learning and experiences.

It was interesting to note that the one individual in the study who had not had to make many decisions for herself as a young child, indeed, had not been allowed to make many of her own decisions until after high school, was

the only one who was unable to decide to assume the 24-hour caregiver role for her loved one. It was the one situation in which decision making did not follow from former life experiences. Perhaps, without the experiences, responsibilities, and practice of decision making as a child, she did not have the basic foundation from which to draw to make decisions as an adult.

4. Developing a partnership with hospice personnel gives caregivers more self-confidence, enables them to provide better care for their loved one, and helps them make better decisions.

Working together as a team, the caregivers developed a close partnership with hospice personnel to provide the care needed for the terminally ill person. This required a type of "internship" in which the learners (caregivers) were encouraged by the partners (hospice personnel) to bring their previous experience and knowledge to the situation in order to become actively involved in problem solving and decision making. According to Seaman and Fellenz (1989), treating adults as partners rather than observers is a good way to encourage them to become independent planners and decision makers who are able to work well with others.

Stuhler-Schlag (1985), in her study investigating the relationships between hospice and families, further

confirmed that forming a partnership was very helpful. It produced a home atmosphere in which shared values, beliefs, and expectations maintained the quality of the patient's life throughout the dying process.

5. Having a strong set of values is an essential factor for better decision making during emotionally stressful times.

According to their responses, all individuals in the study said they had a strong set of values and had been taught right from wrong as children. Having made this value system a part of their life when they were very young was regarded by the individuals as being of enormous help to them as adults, especially when they tried to make decisions when they were emotionally upset. Praying about their decisions and using the Golden Rule made decision making easier, they insisted, and kept their consciences clear.

The commitment to the dying person's wishes was a value that was held by all the families. Honesty, doing unto others, and the acceptance of death as part of life all seemed to make decision making easier. Knowing that they did the best they could for their loved ones continues to help the survivors work through their loss.

Darkenwald and Merriam (1982) proposed that "learning goals often come from needs that are personal or

religious." The writings of Buchanan and Brock (1989) further state that one of the important elements of competence in decision making is that the individual must have a conception of the good or a set of values that are being utilized.

The Golden Rule was considered of great importance by several of the participants, who said that they used it every day because it worked for them. Having the value "Do unto others as you would have others do unto you" helped them decide how to treat others. Using this rule led to greater self-esteem and self-confidence, which in turn led to their being able to make decisions easier.

6. Support (such as marriage partners, family members, friends, and others) helps decision making ability.

The family members in this study came from a middle class, rural group of people and what they experienced was a time of extended family, with all family members involved in common work. The families helped make the loved one's last days comfortable, without the death being extended by technology. Hospice stepped into these family circles and filled the needs of the families, enabling the dying person to experience a more natural death. Hospice support provided the dying person a kind of celebration of life, as well as put spirit into the caregiver and the family.

Since all these terminally ill patients preferred to die at home, it appears that hospice care is an idea whose time has come. The only other alternative that was considered as highly by these families was a hospice room in a hospital. The nursing home was considered but only as a last resort. Again, this shows that the dying person wanted family support, and the family wanted to share every minute they could with their loved one. All participants except one (whose spouse was deceased) said they relied heavily on their spouse for support and advice when making decisions. They were also aided by relatives, friends, and neighbors who were there to support the caregiver during this time.

The relationship which formed between the hospice personnel, the participants' families, and their friends and neighbors helped to give the families more confidence in the caregivers' abilities to provide care. Instruction given by nurses to caregivers about how to interpret changes in their patient's condition gave them signposts to look for and relieved some of their fears of the unknown. They also helped the families reorganize their daily activities to meet the new demands of patient care in the home. Some of the benefits for the caregiver which resulted from this relationship were the same as had occurred in Stuhler-Schlag's study (1985). They were more at ease in asking questions, as well as more independent in

making decisions. Hospice care allowed and encouraged this.

7. Having a decision making strategy was helpful to the caregivers when making decisions during hospice care.

All the participants used various strategies for problem solving and decision making; however, the ones they considered the most important were considering all the options at their disposal and weighing the pros and cons before deciding. Gathering information from hospice personnel, from literature they were given, and from their family and friends gave them options for making decisions. Then they took into consideration what their loved ones wanted and what would be best for them and made their decisions based on the preferences and needs of their loved ones.

The above strategy strongly agrees with the decision making strategy of White (1988), in which he suggested the steps of setting out options, withholding action, and evaluating likely costs and rewards. It also agrees with the Peace Hospice of Montana Patients and Family Bill of Rights. Among many other rights which are included, it affirms the right to share in decision making, the right to maintain control over their own lives, and the right to have the quality of life which they choose (Peace Hospice of Montana, 1991).

8. The industrial age sterilized the dying process and the information age has highlighted it. We have gone full circle and have returned once again to the pioneer way of life by dying at home.

Until the middle of the 1940s, dying was a process that was mainly done in the home. Then the trend changed, and with the advent of new life-saving measures in health care facilities, most people died in hospitals and nursing homes until the latter part of the 20th century (Ahronheim & Weber, 1992, p. 17). Now, near the end of this century (the 1990s), a large number of dying individuals are expressing a sincere desire to die in their own homes with their loved ones standing by.

9. The participants in this study reported that they gained a greater insight into who they were by reviewing their entire life experience during the second interview session. Further, they stated that it gave them a big picture of their lives. They said, "Thank you! I never had the opportunity to talk about my whole life." It appeared to be a type of adult education, wherein the interviewee was not only the learner but was also the teacher. The researcher served in the role of facilitator.

Recommendations

1. Based on the conclusions of this study, it is recommended that families which include a terminally ill person be informed by the attending physician about hospice and a referral for hospice care be given, if desired by the family, when a prognosis of 6 months or less is determined. This would greatly benefit the family by providing help with decision making and would give emotional and physical support to the family in a more timely manner.

2. It is also recommended that a greater effort be made by Peace Hospice of Montana to publicize hospice care as well as to educate people in the community about the services it offers. Only 2 out of the 8 families in this study knew what hospice was and what it provided. This indicates a need for more distribution of knowledge to the community.

This could be accomplished by running a series of short informative articles in the local newspaper every year or two. It would also be helpful to give presentations followed by a discussion period to individuals at the Senior Center and at other facilities and support group meetings where seniors and others gather together. Another option might be to provide hospice information pamphlets to cancer treatment centers and doctors' offices. Preparing a short video with actual

hospice workers and showing it on television as a public service would reach a large number of people. Having an "open house" might be helpful. This type of publicity would not only be informative but would acquaint the public with some of the individuals giving hospice care and take away some of the mystery.

3. A third recommendation would be to include instruction in decision making as a part of our kindergarten through 12th grade school system curricula. It is further recommended that schools provide evidence that they are using real-life problems when teaching decision making to students.

Classes in decision making should also be made available to adults in the communities through continuing education, as well as in the college and university settings. Since many adults have difficulty making decisions during these especially stressful times, the education of adults in decision making is an option that should be considered to meet tomorrow's needs.

There are several methods that may be used in the classroom for learning how to make good and useful decisions. First, for the very young learner, the use of pictures and problems on interactive software for the computer would be helpful. Interaction between a teacher and the students by using face-to-face problem solving

sessions in the classroom with results that directly affect the problem solvers would be useful and practical.

Dividing the students into small groups and giving each group a different problem to solve or decision to make would not only help with decision making but would help with interpersonal actions and cooperation between students.

A second method is brainstorming which uses small groups of 3 to 12 people. A great number of ideas can be generated this way and the rules are simple. No criticism of ideas is allowed, and all members are encouraged to build on each other's ideas. In a 15 minute brainstorming session all ideas are written down, and then following the session the ideas are organized and priorities are set for discussion and action.

Third, the use of creativity can also be exciting for making decisions. One level of creativity consists of making new connections by using one's imagination and gathering information about goals and methods from several sources such as colleagues, other institutions, a supervisor, a friend, or journals. Then these ideas are synthesized into an individual's totally new method for decision making. Another level of creativity is to expand one's frontiers by generating far-out inventions and by running the risk of testing them out to see if they work.

Finally, another method involves clearly setting your goals and objectives and defining them to some criteria. In this way an individual will know exactly when the goals and objectives have been met. Reg Herman (1982) also advises individuals "to run the risk of naming their decisions in order to enjoy continuous challenges in their lives."

4. Peace Hospice of Montana currently uses a team approach and a partnership method of working with their patients; therefore, the researcher's fourth recommendation is that they continue to do so, because treating adults as equal partners encourages family members to become independent planners and decision makers who can work well with others. This is a vital component in maintaining the patient in the home care atmosphere.

5. The researcher recommends that a course in creating or affirming personal value systems be offered in all schools and colleges. Having clear values made decision making easier for those individuals in this study undergoing the emotional stress of hospice.

6. It is recommended that hospice families encourage their spouse, family members, and friends to take an active part in the care and support of the dying person. This in turn increases the self-confidence of the caregiver and

improves their decision making ability. This could be accomplished by hospice offering classes or workshops on caregiving and interacting with the dying. These classes could be taken by hospice families and friends or by those in the community who were interested in improving their caregiving skills.

7. It is recommended that hospice teach their patients and caregivers a decision making strategy if they do not already have one that they actually use. The social workers would be ideal to teach this skill because the nature of their work includes problem solving and decision making.

8. It is recommended that further research be done in the area of decision making by caregivers of hospice care using a larger number of participants. It is also recommended that research be done using a younger age group (perhaps Baby Boomers) who have lived only in cities to determine the difference between them and the older individuals in this study. In addition, a study examining the interaction between hospice caregivers and hospice professionals regarding the personality type of the caregiver and the personality type of hospice personnel they work best with would be useful.

Decision making is healthy struggle. Struggle serves real self, real growth, and real success. Struggle can be difficult, but it is not suffering. Struggle is the mobilization of inner resources and concentrating everything in ourselves on the problem at hand. When we struggle, we engage in the process of healthy change and growth. We exercise ourselves and flex all our muscles--physical, intellectual, and emotional--in the service of full living.
(Rubin, 1985, p. 192)

REFERENCES

- Ahronheim, J., & Weber, D. (1992). Final passages: Positive choices for the dying and their loved ones. New York: Simon & Schuster.
- Arnold, E. (1992). USA hospice care in the 1990s. Palliative Medicine--A Multiprofessional Journal, 6(2), 158-165.
- Ausubel, D. P. (1982). Cognitive structure and the facilitation of meaningful verbal learning. In R. Anderson & D. Ausubel (Eds.), Readings in the psychology of cognition, p. 5. New York: Holt, Rinehart, & Winston.
- Barer-Stein, T., & Draper, J. A. (Eds.). (1988). The Craft of teaching adults. Toronto, Ontario, Canada: Culture Concepts, Inc.
- Bayles, E. E. (1970). Insight: Its nature and its place in education. Colorado Journal of Educational Research, 9(2), 14-20.
- Bertman, S. (1991). Facing death: Images, insights, and intervention. New York: Taylor & Francis.
- Bete, C. L. (1992). About hospice under Medicare. South Deerfield, MA: Channing L. Bete Co.
- Bete, C. L. (1993). About hospice. South Deerfield, MA: Channing L. Bete Co.
- Bloom, B. S. (1976). Human characteristics and school learning. New York: McGraw-Hill.
- Buchanan, A. E., & Brock, D. W. (1989). Deciding for others: The ethics of surrogate decision making. New York: Cambridge University Press.
- Cabot, H., & Kahl, J. A. (1953). Human relations, concept, and cases in concrete social science. Cambridge: Harvard University Press.
- Cameron, C. (1982). The case method as an instructional strategy in adult and continuing education. Unpublished Manuscript.
- Chase, D. (1986). Dying at home with hospice. St. Louis, MO: Mosby.
- Conti, G. J. (1977). Rebels with a cause: Myles Horton and Paulo Freire. Community College Review, 5(1), 40.

- Crystal, R. (1985). Perceptions of dying: A study of hospice volunteers. Ed.D. Dissertation, Boston University.
- Daleo, R. E. (1986). Taking care of the caregiver. The American Journal of Hospice Care, 3(5), 33-38.
- Darkenwald, G. G., & Merriam, S. B. (1982). Adult education: Foundations of practice. New York: Harper Collins.
- Dobihal, E. F. (July, 1974). Talk of terminal care. Connecticut Medicine, 365.
- Dooley, A., & Skinner, W. (1977). Casing case methods [monograph]. Harvard Business School Series. Cambridge: Harvard University Press.
- Feifel, H. (1977). New meanings of death. New York: McGraw-Hill.
- Gagne, R. M., & Smith, E. C. (1962). A study of the effect of verbalization on problem solving. Journal of Experimental Psychology, 63, 12-18.
- Gold, M. (1983). Life support: What families say about hospital, hospice, and home care for the fatally ill. Mount Vernon, NY: Consumers Union Foundation.
- Greenwald, H. (1973). Direct decision therapy. San Diego: EdITs.
- Holden, C. (1976). Hospice: For the dying, relief from pain and fear. Science, 193, 389.
- Houle, C. O. (1972). The design of education. San Francisco: Jossey-Bass.
- Johnson, S. (1992). Yes or no: The guide to better decisions. New York: Harper Collins.
- Knowles, M. (1980). The Modern Practice of Adult Education (Rev. ed.). Chicago: Association Press/Follett.
- Kubler-Ross, E. (1969). On death and dying. New York: MacMillan.
- Leloudis, D., & Pole, L. (1985). The American Journal of Hospice Care, 2(6), 30-34.

- Lewis, C. S. (1961). A grief observed. New York: Seabury Press.
- Lindeman, E. (1961) The Meaning of Adult Education. Montreal: Harvest House.
- Linskie, R. (1983). The learning process: Theory and practice. Boston: University Press of America.
- Montana State University College of Nursing. (1989). The Montana Family Cancer Project--Phase II. Bozeman, MT: Montana State University.
- National Association for Home Care. (1995, February). HHA: 1995, Blueprints for action: Hospice fact sheet. Home Care News, 11.
- National Hospice Organization. (1990). Statistical snapshot: 1989. Hospice News.
- Peace Hospice of Montana. (1989). Patient and Family Caregiver Manual. Great Falls, MT: Columbus Hospital.
- Rhymes, J. (1990). Hospice care in America. JAMA, 264, 359-371.
- Rogers, Carl. (1969). Freedom to learn: A view of what education might become. Columbus, OH: Charles E. Merrill Publishing.
- Rossmann, P. (1979). Hospice: Creating new models of care for the terminally ill. New York: Fawcett Columbine Books.
- Rubin, T. I. (1985). Overcoming indecisiveness. New York: Harper & Row.
- Saunders, C. (1973). The last frontier. In R. B. Reeves et al., Pastoral care of the dying and the bereaved: Selected readings. New York: Health Sciences Publishing Corporation.
- Seaman, D. F., & Fellenz, R. A. (1989). Effective strategies for teaching adults. Columbus, OH: Merrill.
- Smith, R. M. (1982). Learning how to learn. Chicago: Follett.

- Sourkes, B. (1987). Views of the deepening shade: Psychological aspects of life-threatening illness. The American Journal of Hospice Care, 4(3), 22-29.
- Stuhler-Schlag, M. K. (1985). An ethnography of hospice home care. Ed.D. Dissertation, Rutgers University.
- Thorndike, E. L. (1968). Human learning. Cambridge, MA: M.I.T. Press.
- Tough, A. (1971). The adult's learning projects: A fresh approach to theory and practice in adult learning. Toronto, Canada: Ontario Institute for Studies in Education.
- Wheeler, D. D., & Janis, I. L. (1980). A practical guide for making decisions. New York: MacMillan.
- White, R. T. (1988). Learning science. Oxford, U.K.: Basil Blackwell.
- Winston, L. W. (1989). Institutional ethics committee: A function of organizational characteristics. Doctor of Public Administration Dissertation, University of Southern California.

APPENDICES

APPENDIX A
INTERVIEW QUESTIONS

PATIENT'S HISTORY:

- 1) Please describe the situation in which hospice care was used. Relationship? Age? Type of illness/injury? Length of illness/injury? Treatment? Length of time used?
- 2) When did you learn that the condition was terminal? Who told you? What did they say? Were they supportive? Time frame: learned terminal and hospice contacted?

HOSPICE CARE:

- 3) Tell me about your experience with hospice. Who told you about Hospice? Had you ever heard of Hospice?
- 4a) How did your loved one feel about this? Did he/she want to die at home?
- b) Needs of other family members in coming to understand the situation? Family members out of town?
- 5) What were the good and bad points of hospice care? How did they help you and your family?

EMOTIONS, AND REACTIONS OF FAMILY:

- 6) How did you feel about your loved one dying at home? At first, how did you feel about accepting Hospice care for your loved one? How did the family feel?
- 7) Tell me about your attitude and beliefs about death and dying. What physical, mental, emotional, or spiritual needs did you have that prompted you to use hospice care?
- 8a) Were other persons involved in helping care for your loved one?
- b) What other options would you have considered if you found you were physically or emotionally unable to continue caring for your loved one?

DECISION-MAKING:

- 9) Were you or your family prepared to make this decision? What helped you the most when making decisions? Life experiences?
- 10) Were there blocks/hindrances to your decision-making? How do you make important decisions?

- 11) Who made the final decision to accept Hospice care?
Who or what helped most?

LIFELONG LEARNING:

- 12) Beginning with your earliest recall, tell me what your responsibilities were in the family and what you learned from them. Schooling? Work? What caregiver skills had you already learned before you decided to be a caregiver in the home?

Adapted from Peace Hospice of Montana (1994) and Montana State University College of Nursing (1989).

APPENDIX B
HOSPICE EXPERTS

HOSPICE EXPERTS

1. Bonnie Spade, R. N., Director of Peace Hospice of Montana
2. Mary Gray, R. N., Hospice Patient Care Manager
3. Jeanne Dussault, L.P.C., Hospice Social Worker
4. Jo Marie Einan, Hospice Volunteer
5. Marilyn Parker, Hospice Operations Assistant

APPENDIX C
BALANCE SHEET FOR DECISION MAKING

EXPLANATION OF BALANCE SHEET FOR DECISION MAKING

A balance sheet may prove to be helpful to the caregiver when trying to make a decision while undergoing this stressful period. The following balance sheet shows some of the possible expected consequences of tangible gains and losses for oneself and for others, as well as possible aspects of self-approval and self-disapproval when comparing in-home care with nursing home care. In addition, it lists possible aspects of approval and disapproval from others in regard to in-home care versus nursing home care for the patient. See Table 4 for a balance sheet illustrating these points (adapted from Wheeler and Janis, 1980, pp. 62-63).

Table 4. Decision Making: A Balance Sheet (Plus and Minus Version).

Expected Consequences	24-Hour Caregiver Status	
	Hospice (In-Home Care)	Nursing Home Care
Tangible Gains (+) for Self	Satisfaction in knowing loved one is happier. Aware of her condition at all times. Feeling of doing something important for loved one.	Have more time for myself. Able to continue working. Less responsibility. Have nurse call when death imminent.
Tangible Losses (-) for Self	Feelings of inadequacy and heavy responsibility. Possibility of burnout. Loss of sleep. No social life. Fear of death.	Unaware of her condition at times. Worry about her feeling abandoned. Guilt feelings. Knowing that food is fair/poor.
Tangible Gains (+) for Others	Familiar surroundings. Less confusion. Less feeling of abandonment. More freedom/choices. More personal mobility. More contact/friends. Favorite foods.	Less family burden. Consistent 24-hour care. Quicker access to doctor. More objectivity in care/decisions made by others.
Tangible Losses (-) for Others	Feeling death is near. Possibly depression. Feeling a burden on family.	Unfamiliar place. Many "strangers." More confusion. Less caring atmosphere. Poor food and poor eating habits.
Self-Approval (+)	Satisfaction of having affairs in order. Making last days pleasant. Satisfaction of caring for loved one.	Feeling competent people caring for loved one. Relief from stress. Quality time during visitation.

Table 4. Continued.

Expected Consequences	24-Hour Caregiver Status	
	Hospice (In-Home Care)	Nursing Home Care
Self- Disapproval (-)	Feeling inadequate at times. Lack of objectivity when making decisions. Worry and grief.	Guilt/fear that care is poor. Not caring for loved one by family. Worry regarding abandonment.
Approval from Others (+)	Close family approval. Friends visit oftener. Loved one happier in own surroundings.	Social circle approval. Able to continue working (job).
Disapproval from Others (-)	Family feels neglected. Friends feel neglected due to 24-hour care.	Family/friends may feel one is shirking duty or that less love felt for loved one/uncaring attitude.

Adapted from Wheeler and Janis, 1980, pp. 62-63.

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