

FAMILY DECISION MAKING IN TERMINAL CANCER: A DESCRIPTIVE
STUDY

by

Linda J. Kristjanson

A thesis
presented to the University of Manitoba
in partial fulfillment of the
requirements for the degree of
Master of Nursing
in
School of Nursing
University of Manitoba

Winnipeg, Manitoba, 1983

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ABSTRACT

This thesis is a descriptive study which addresses the general research question: How do families perceive their involvement in terminal care decisions? The study involved in-depth interviews of families who had experienced the death of a family member within the past year. Interviews and field notes were analyzed using a method of content analysis called constant comparative analysis. Six categories were identified that described the families' perceptions of their participation in the terminal care experience. These were:

1. The control over decisions defined by who had the majority of decision control and the setting within which this decision making occurred.
2. The information used as a basis for terminal care decisions.
3. The meaning of the situation based upon the families' interpretation of information and experience.
4. Patterns and characteristics of family interactions related to terminal care decisions.
5. The events, experiences, and decisions involved with planning for the person's death.

6. The effects of the terminal care process on survivors. The effects were in response to two properties:
 - (a) the congruence families experienced between the preferred decision control and the actual decision control in the care experience, and
 - (b) the loss of the family member.

The study describes and defines these six categories using excerpts from the interviews and field notes to illustrate the analysis. Implications for changes in health care delivery and suggestions for future research are discussed.

ACKNOWLEDGEMENTS

The researcher is indebted to her advisor, Professor Lesley Degner, who facilitated a stimulating learning experience and an excitement for nursing research. The contributions of Professor Patricia Farrell are appreciated, especially for her assistance in the conceptual phase of the research. The author also extends thanks to Professor Eleanor Adaskin for generously sharing her theoretical and clinical knowledge of families and interviewing techniques. In the early stages of the research plan the enthusiasm and guidance of Dr. Helen Glass were very helpful. Her input is warmly appreciated.

The study could not have been conducted without the assistance of Dr. Paul Henteleff and Mrs. Ann Charles at St. Boniface General Hospital. The investigator would also like to thank the Manitoba Health Research Council for their generous financial support.

The researcher would especially like to acknowledge the participants in this study. These families willingly shared experiences that were personal and often stressful. It was their interest in facilitating knowledge in the area of terminal care that made the research possible. Therefore, the study is dedicated to these people.

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Chapter I

INTRODUCTION

1.1 STATEMENT OF THE PROBLEM

There is a growing assumption in the recent literature that dying patients and their families should be involved in decisions about terminal care (Gottheil, 1976; Vertinsky, Thompson, & Uyeno, 1974). This assumption arises from the conflicting results of several studies of consumer participation in health care decisions. The twofold belief, that all individuals and families wish to participate to the same extent in terminal care decisions, and that more participation will necessarily lead to improved health care outcomes, may not be warranted. This study questions the underlying assumption that all families should participate to the same extent in health-illness decisions and that more participation leads to better health for family members.

A more conservative assumption is that the degree to which the families wish to participate may vary. The aim of this study then, is to examine families' perceptions of (a) their desired and actual participation in terminal care decisions, and (b) the degree of congruence between these two variables.

Decision making has been studied in many fields other than health care. The application of the general decision making literature to terminal illness situations presents difficulties. The assumptions that arise in other fields of decision theory, such as rationality, authority and freedom to make decisions, do not necessarily exist in health-illness situations. For example, Curtin (1979) and Donabedian (1973) suggested that structural components of the health care system may affect the decision making process. In life-death decisions, families and patients often lack the information to make rational decisions and may not feel they have the authority to participate in decisions. As Freidson (1961) noted, the physician in North American culture has been seen as an awesome and powerful figure, with the result that patients have often accepted less than satisfactory treatment. For example, Darling (1977) found that although parents of children with Spina Bifida had numerous misgivings about their children's medical treatment, parents had never complained to a doctor directly.

Many studies (Martocchio, 1982; Glaser & Strauss, 1965; Bradley, 1978; Baldi, 1974; Bates, 1979) identified the power structure in the relationship between patients and health care providers as significant to decision making. Murray (1974) studied the decision making process related to psychiatric treatment of inpatients and outpatients. Her findings indicated that uneven power held by patients and hospi-

tal staff was the most critical aspect affecting decision making communication.

A number of researchers (Degner, Beaton & Glass, 1981; Donovan, 1976; Glaser & Strauss, 1965) described the process of decision making in terminal illness situations as susceptible to communication problems. For example, symbols were often used by health care providers to communicate care decisions in terminal situations. Symbolic communication involved the use of certain words, sentences or flashers to communicate information related to life-death decision making. The use of symbolic communication led to difficulties. "Patients and families were excluded from understanding that certain decisions had already been made about the care" (Degner et al., 1981, p. 294). One of the most distressing aspects of participation in life-death decision making for family members was a lack of communication with health care providers (Degner et al., 1981). It is recognized then, that there are imbalances in power and authority between individuals involved in terminal care decisions. This power imbalance is skewed in the direction of health care providers and physicians in particular. The literature also indicates that the stressful nature of terminal illness may interfere with clear communication. Given these factors, how do families communicate their preferences about terminal care decisions? It has been observed that families vary in the extent to which they actually participate in decisions related to

the care of a terminally ill family member (Degner et al., 1981; Sorenson, 1974; Martocchio, 1982). It appears that there are different obstacles to families' participation. However, no studies have described how families themselves view their actual participation or their preferred participation in terminal care decisions. Before one can pursue the assumption that family participation in decision making is desirable, an understanding of the process as seen by families is necessary.

The extent to which families prefer to participate in terminal care decisions and the extent to which they actually participate in these decisions may vary in degree of congruence. How families experience this degree of congruence, or, if in fact they can articulate this variable has not been explored. "Families do express frustration related to a need for more information about terminal care events" (Benoliel, 1972, p. 199). Darling (1977) also described the anxiety families identified from not knowing more about the terminal care process. Families felt handicapped by the lack of time given them to consider decisions in which they were involved. It appears then, that elements within the terminal care process and decisions related to this experience are described as stressful. Stress has been described as an energy utilizing state (Selye, 1956). Decision making itself requires energy use. It is reasoned then, that the stress that may result from an incongruence between families' de-

sired and actual participation in terminal care decisions will involve energy expenditure.

As nurses, we are interested in the decision making process as it affects energy expenditure and the health of families. Health is a process involving energy, that is continually evolving and changing with the developmental stages and situational stresses of man (Bruhn, Cordova, Williams, & Fuentes, 1977; Dunn, 1959; Archer & Fleshman, 1979; School of Nursing, University of Manitoba, 1979). Therefore, processes that involve energy use, as in the work of living, will affect the health of the individual or group. There is substantial literature to support the notion that the family is involved in, and responds to an illness or deviation in the health of one member as an interactional unit (Weakland, 1977; Bursten, 1965). There is an increasing awareness in recent years that human disease, in addition to a pathology, also has an ecology. The patient's emotional involvement in the family system constitutes a major aspect of that ecology which cannot be ignored (Meissner, 1966). It has also been identified that family members may experience symptoms or deviations from illness when someone in the family is ill. These symptoms include both physiological and psychological manifestations (Kreitman, 1964; Henker, 1964). There is some evidence, most simply, that interaction can and does influence bodily functions (Weakland, 1977). There is knowledge for example, that emotions often obviously and markedly af-

fect such bodily functions as blood circulation and hormonal secretion (Weakland, 1977). The question of more lasting and profound bodily changes, such as are involved in disease, is a more difficult one, but again, both lay and professional observers - from Dunbar (1954) to Selye (1956), have been seriously concerned with the significance of experience for the gravest diseases. Herman (1955) believes that the fact that emotional phenomena accompany or lead to physical phenomena is undisputed. It is also well known that factors in the psychological pattern or events in the life of the patient have great influence on the progress or amelioration of the disease state.

These writings focus on the relationship between emotion or stress and bodily functions of the individual. Stress and emotion all depend greatly on communication interaction (Weakland, 1977). This may be only a difference of conception and phrasing, but the study of families must articulate this component. Thus, there is, usually under other names, considerable and varied evidence that bodily functions can be and are influenced by communicative interaction - one of which might be decision making.

The health of families in the bereavement period has also been described in terms of the physical and emotional symptomatology of grief (Kutscher, 1973). The bereaved person often expresses a multitude of symptoms, as Lindemann's (1944) classic work on grief identified. Kubler-Ross (1969)

and Glaser and Strauss (1965) refer to the fatigue experienced by families having dealt with the death of a family member. These writings indicated that there was a high percentage of somatic symptoms experienced by the surviving family members.

A number of extensive studies have produced data which indicate "a significantly higher morbidity rate among the bereaved (particularly following the loss of a spouse and especially in older age groups) and, more importantly even, a higher rate of mortality during the first six months of bereavement which gradually declines" (Kutscher, 1973, p. 15). Many writers describe the psychological symptoms expressed by these individuals. The feelings expressed included guilt, grief and resentment (Kubler-Ross, 1969; Parkes, 1972; Clayton, 1969). The literature supports the notion that the health of families who have experienced the death of a member is affected. To what extent participation or non-participation in decisions about the terminally ill family member contributed to impairment of the health of surviving family members has not been identified.

As health care providers, we cannot alleviate the stress of family participation without an accurate description of this experience as seen by families. Similarly, we cannot determine the appropriate role of family participation in terminal care decisions without such a description. The purpose of this study is to explore the first part of this re-

search problem through a systematic and accurate description of the decision making process as seen by families.

Chapter II
REVIEW OF LITERATURE

2.1 INTRODUCTION

A review of the literature related to life-death decision making resulted in the identification of several concepts. The research was categorized into concepts that provided a framework within which to view the literature. Studies related to terminal care decisions provided a perspective of some of the issues related to the decision making process. The notion of power and control over terminal care decisions permitted an awareness of some of the structural factors that affect decision making. A third concept that emerged was the definition or label of the terminal care situation by those participating in the process. It was noted that the definition of the situation was central to the decision making process. The literature also described a set of findings classified as patterns of dying, which identified the variation in duration and course of the terminal process. The family dynamics in terminal care situations was also affected by the experience of participating in care and decisions. The general impact of terminal cancer on the health of the family members emerged in the literature as a significant component of the situation. The writings related

to the health of families led to an exploration in the literature of definitions of health. The concept that surfaced in this work was the notion of health as energy use, which provided a theoretical understanding of the energy used in the work of living with terminal illness. These seven concepts provided the background within which the nature of life-death decision making was described.

2.2 TERMINAL CARE DECISIONS

A review of the literature from 1970 to the present indicates that research related to families' participation in terminal care decisions is limited. The studies pursued in nursing and health care have described the stressful nature of decision making in terminal illness situations (Degner et al., 1981; Kastenbaum, 1976). The work has not examined the elements of the decision making process that were seen as stressful by patients and families.

A study of interest was one done by Degner et al. (1981). They utilized a grounded theory approach to study the impact of participation in curative and palliative care. The researchers found that participation in the care of life threatened individuals was clearly stressful. The element of accountability emerged in this work. It was found that all groups involved in life-death decisions felt a degree of accountability for the decisions made. The notion of accountability in this study identifies a particularly significant

consideration in the study of the impact of decisions on families in terminal care situations. Even though decisions may be made without family input, families may nonetheless feel accountable for decisions made. This element is worthy of further study.

The variation in degree of involvement in decisions by families was evident in the literature. One study suggests that many patients do prefer control over decision making (Cassileth, Zupkis, Sutton-Smith, & March, 1980). However, selection bias may have resulted in an overestimation of the proportion of patients desiring control. Degner et al. (1981) found that in many cases patients have no desire to participate in decisions about their treatment, and will steadfastly refuse to do so even when the physician goes to great lengths to lay out the options for them. Other patients expect to participate at least to some degree in decisions about their treatment, and become frustrated if not allowed to do so. The variation in reported preferences in participation in terminal care decisions leads one to ask what effects the frustration of not participating has on those who would prefer more involvement. Also, for those who do not wish to have control over decisions, how does pressure to be involved affect them?

2.3 POWER AND CONTROL IN DECISION MAKING

In terminal care situations the interaction of a number of individuals is usually the case. Those involved vary in their degree of participation in decision making, willingness to participate in decisions, ability and authority to participate and beliefs about who participates (Glaser & Strauss, 1968; Bradley, 1978; Bates, 1979; Degner et al., 1981; Freidson, 1961). The reasons for the variation in families' involvement in decisions have been postulated as being partly related to structural limits in the situation, such as differences in power and authority that exist between health care providers and families (Darling, 1977; Martocchio, 1982). Deficits in information has also been described as an underlying handicap to more active patient and family participation in health-illness decisions (Donovan, 1976; Curtin, 1979).

Demographic factors such as age, social class and education have been identified as significant to the degree of involvement in health care decisions permitted to families by health care providers (Martocchio, 1982; Sudnow, 1967). Ineffective communication processes have been described as a barrier to participation in decision making by families, patients and health professionals (Donnelly, Mengel, & Sutterley, 1980; Degner et al., 1981).

Much of the decision making literature in health-illness situations focuses upon decisions made by physicians regard-

ing the extent of active treatment to pursue and decisions to resuscitate or not resuscitate a patient (Drane, 1975; Denger, 1974; Weightman, 1977; Darling, 1977). The involvement of physicians in decisions related to illness matters brings legal authority to the situation. However, these decisions are laden with ethical or value considerations.

One physician, Henteleff (1978) underscores the point that ethical values can sometimes tend to conflict in treatment decisions in the care of the dying. Basically, the value placed on life calls for life-saving actions; the value placed on human dignity calls for restraint of futile assaults on failing bodies. "Decisions are often based on medical prognosis which is not a matter of virtual certainty" (Walton & Fleming, 1980, p. 59). The physician, nurse, family and patient all vary in religion, ethnicity, social class, culture and knowledge. These factors contribute to imbalances in decision making abilities and communication.

Informed consent is discussed in the literature as an important guideline for health care providers to use in terminal care situations. Informed is understood to mean that the patient has had a physician's interpretation of his condition, its risks, and the options for medical intervention put in terms which he can use as a basis for his decisions. The consent is important in law; the informing is important in the patient's human development (Henteleff, 1978). Henteleff (1978) also believes that the family, ideally, should

be informed as well, in order for the patient to anticipate the effects of his choice.

Other authors (Flaherty, 1982; Benoliel, 1978) have observed that physicians believe that they alone are ethically and legally responsible for the totality of the health and illness care provided to patients; they fail to recognize that the health care team includes patients and their families, nurses and other health professionals. An imbalance in power between health professionals and patients and families is a reoccurring theme in the literature. The studies generally looked at who made decisions and considered structural factors in this light. The dynamics of the process were not explored.

Martocchio (1982) studied the social context of dying patients in hospitals and observed that in health-illness decisions not all actors negotiated from equal positions of strength. Generally, health care providers had greater strength than patients and families in negotiations. She found that the sources of power that provided stronger negotiating positions included information, prior experience and continuity and duration of interactions.

These structural and internal processes affecting the health team, patient and families' decision making may result in differences between how individuals prefer to participate in decisions and how they actually participate. Any incongruence between desired participation and actual par-

participation may be frustrating for families. There may also be other components of the decision making process that families experience as stressful. An understanding of these components is important to health providers involved in such decisions.

2.4 DEFINING THE TERMINAL CARE SITUATION

A third theme that arose in the literature was the process involved in defining the situation as terminal. Glaser and Strauss (1965) described types of awareness contexts of those interacting in the situation. Awareness contexts are "what each interacting person knows of the patients's defined status, along with his recognition of the other's awareness of his own definition" (p. 10). It is the context within which these people interact while taking cognizance of it. Plainly, that context is complex, and it may change over time, especially as the patient's condition worsens and as explicit or implicit messages of his condition get through to him. The types of awareness contexts described included:

(a) closed awareness - the individual does not recognize his impending death, (b) suspicion awareness - involves a patient who does not know, but only suspects with varying degrees of certainty that the hospital personnel believe him to be dying, (c) mutual pretense - exists when patient and staff both know that the patient is dying but pretend otherwise, when both agree to act as if he were going to live, then a context of mutual pretense exists, (d) open awareness - occurs whenever both staff and patient know that he is dying, and acknowledge it in their actions (Glaser & Strauss, 1968).

It is clear that individuals will vary in their awareness contexts of a situation which will affect the decisions and actions they take as a family. How is family consensus about the definition of the situation achieved? The communication and interactions of family members would appear to be central to this defining process.

The significance of defining or labelling the terminal care situation has also been identified by other researchers as basic to the interactions of those involved. Martocchio (1982) found that there was no well-defined place in time when the person was initially labelled as dying by all interactors. Crane (1975) found that physicians' definitions of salvageable patients was affected by their judgments of patient's ability to assume a social role. Darling (1977) found vast differences between physician's and parents' definitions of the birth care of a child with spina bifida. Benoliel (1972) described the impact of a life threatening disease in a child as catastrophic for parents. Kastenbaum (1976) found four different personifications of death described by individuals that reflected significant variation in the meaning of death. He also suggested that there was a cultural definition of death that influenced the meaning of the experience for people.

Weisman (1979) describes a range of definitions of a terminal situation that cancer patients express. He acknowledges that denial may be a phase of coping that defines the

situation for patients and families. Weisman (1979) also identified the phenomenon of middle knowledge, the mixture between awareness, acceptance and denial, which means knowing and not knowing at the same time.

The complexities and dynamic component of defining the patient as terminal are important to realize when one is studying decisions made during this period. It is likely that the interactors in a terminal care situation will define the context differently. Therefore, their communication and involvement in decisions made within these contexts will be effected.

2.5 PATTERNS OF DYING

The literature also describes different types or patterns of dying. Martocchio (1982) used participant observation to identify patterns, processes or qualities which typify the situation of and surrounding dying persons. She identified four patterns of living and dying. These were described as:

- (1) Peaks and Valleys in the course of the illness,
- (2) Descending Plateaus that represented general deterioration with periods of no change,
- (3) Downward Slopes where the disease was progressive and deteriorating, and
- (4) Gradual Slants that reflected a more slowly moving, even descent to poorer health (Martocchio, 1982, p. 69).

The differences in these patterns is significant to the decision making process. Patients and families will have different input into decisions if the disease is fast progressing, in comparison to a more gradual and expected decline.

Glaser and Strauss (1968) also described the pattern of dying in terms of dying trajectories. Dying trajectories occur over time: they have duration. Also, a trajectory has shape: it can be graphed. These are perceived properties, therefore dying trajectories are perceived courses of dying rather than the actual courses.

The pattern or trajectory and the events within the course must be understood then, in terms of how the process is perceived by those involved. The element of time is described in the literature as significant in defining, understanding and participating in terminal care decisions. Darling (1977) found that even when given truly informed consent, families felt handicapped by the lack of time to consider their decisions fully. Griffin (1975) identified the importance of enough time for families to understand the events in the terminal care situation in order to work through their guilt and anger. Therefore, any study of dying must take into account the fact that dying takes time (Glaser & Strauss, 1968).

2.6 FAMILY DYNAMICS

Another theme present in the literature was the perception of the family as an integral subsystem in the larger societal order. Numerous writers in the fields of family therapy, social work, nursing and more recently medicine are acknowledging the significance of understanding the family

dynamics as they relate to an illness episode. Richardson wrote a book as early as 1948, Patients Have Families, acknowledging the family as a unit of illness with patterns of functioning, deviations in equilibrium, and a role in treatment. There was emphasis on clinical data placed within a general systems theory. He stated, "the doctor who treats the patient for a chronic disease may be observing one aspect of a reciprocating system of which he may be aware if he inquires into the health of the family" (Richardson, 1948, p. 97). The notion of inquiry into health of the family, also led to more direct observation of families. However, information about the internal processes and life cycles of families is still limited. Longitudinal studies based on observation of the family have not been done. Only self-report surveys, in which family members are asked about their lives are available, and they have proved to be highly unreliable. What other information we have is based upon families entering therapy when they are in trouble, and so we have observed different stages in the family cycle without knowing what came before or what naturally follows (Haley, 1973). It appears that there is a need for information about how families as a unit respond to normal events, as well as stresses such as terminal illness and the processes within that experience.

Support for a broader context in which illness in one individual is viewed comes from Grolnick's (1972) review of

the literature on a family perspective of psychosomatic factors in illness. He concluded that the family functions as a system in relation to a physically ill member. An outbreak of illness has an active feedback with the family system. It may stabilize it, resulting in medical attendance patterns of chronic illness, or feedback may further unsettle things, resulting in psychosomatic outbreaks or other dysfunction in other members. Richardson (1948) stated, "It is not so much the kind of disease as its duration and seriousness which....disturbed the family equilibrium." He conceptualized feedback cycles between the somatic and psychic within and among members of the family.

Haley (1973) believed that the arena of human passion is ordinary family life. He stated that it is becoming more evident that families undergo a developmental process over time, and human distress and psychiatric symptoms appear when this process is disrupted. Milton Erickson (1973) also believed that symptoms of illness appear when there is a dislocation or interruption in the unfolding life cycle of a family or other natural group. The symptom is a signal that a family has difficulty in getting past a stage in the life cycle. It would seem then, that the study of psychological health has moved from an individual focus to a study of interactions between two individuals (mother and child), to a consideration of the whole family as a social unit.

Weakland (1977) believed that once an illness exists, interaction in a family may be relevant to its course and outcome, for better or worse. Such an influence might be direct - that is, one form of interaction might interfere with the body's functions of resistance and healing, while another might facilitate these. Less directly, yet perhaps equally significantly, interactive factors might function to help or hamper the useful application of medical treatment for a given problem. To take a simple example, the success of current therapies for cancer depends greatly on whether the disease is recognized and treated early or not. As Shands (1970) and others have noted, failure of recognition in many cases appears to involve avoidance or denial, not just the overlooking of minor signs; certainly interaction might be important to this.

Another study of interest was one by Otto (1966) to examine the use of family strengths in the social work treatment process. The definition of family strengths used in the study was "those factors or forces that contribute to family unity and solidarity and that foster the development for potentials within the family" (Otto, 1966, p. 88). This study together with an extensive search of the literature, covering a twenty-year period resulted in a tentative framework of family strengths. One of the strengths identified was a family's ability to communicate with each other. This included the ability to express a wide range of emotions and

feelings, as well as communicate ideas, beliefs, and values. Communication was seen as verbal expression as well as sensitive listening. The study identified consensual decision making based on open communication as a family strength. The study also labelled a family's ability to use a crisis constructively, as a strength. For example, loss of a family member can result in a united and supportive attack that can bring a family closer together in understanding and affection for each other (Otto, 1966).

The literature also described, to a lesser extent, the family dynamics in the specific crisis of terminal care situations. Barton (1977) described the role changes that occurred in families with a dying member. He identified issues of independence and dependence that created stress for those involved. Differences in family members' perceptions of a situation contributed to conflict, as interactions between members were out of sync.

Gyulay (1975) studied survivors of children who had died from cancer. She observed that rarely, if ever, were parents in the same stage of grief. Fathers were often pushed out of participation in care and later expressed guilt, frustration and anger at not participating.

The literature described the changes in family roles imposed by the illness of one member. "The inability of one or more members to fulfill their obligations to the group requires reassignment of role tasks to others, who, temporarily

ly at least, perform not only their own duties, but the incapable individual's duties as well" (Coe, 1970, p. 101). The complementary roles of family as care givers may be suitable for a period of time. However, the assumption of added roles can place an additional strain on family members, who, are dealing with fears of the future and anxieties in relation to the phases of the illness (Carlson, Jackson, & Reader, 1967; Callahan, 1966). Family members asked to take on a role as a decision maker may find this difficult if the role is new to them. There may also be individuals in the family who normally fulfill decision making roles and lose the role in the course of the interactions. It is important to study the relatively unexamined family dynamics involved in terminal care decisions. The interactions, patterns, and communications are complex and uncharted. The communications related to decisions is particularly significant to the functioning of families in these situations.

2.7 HEALTH OF FAMILY MEMBERS

A number of studies describe the general impact of terminal cancer on the health of family members. Lefebvre (1978) cited changes in appetite, sexual activity and sleep in families where a parent had terminal cancer. Degrange (1982) noted the differences in health between widows who had been prepared for the death of a spouse and those who had not

been prepared. Kutscher (1973) also reported that various illnesses are more frequent among survivors than in matched comparison groups. One researcher found that sometimes bereavement leads to serious somatic and psychological symptoms during the next year or two (Parkes, 1970). Weisman (1962) observed that not only are so-called psychosomatic illnesses very common in survivors, but the onset of various unquestionably organic diseases can be traced to such psychosocial events as bereavement, depression, despair.

Gyulay (1975) found that the siblings of the terminally ill child often developed the same symptoms as the ill child, even to the point of side-effects from the chemotherapy. The literature indicates that the health of the family members who have experienced the death of a member is affected. The significance of the stresses of the decision making process within the terminal care experience has not been studied in relation to the impact on family health.

2.8 HEALTH AS ENERGY USE

The discussion in the literature related to the health of survivors guided the literature review into readings of descriptions and definitions of health. Many of the descriptions of health talked of it as a dynamic process involving adaptation to situational and developmental stresses (Dunn, 1959; Bruhn, 1977). A number of recent writings on health and illness described the concept, energy, as significant to

well-being. At a purely objective, scientific level Krebs (1979) explains energy as necessary for building up and maintaining living structures and for every activity associated with life, such as movement, growth, secretion or the synthesis of body cell materials including hormones and enzymes. The literature on biofeedback training postulates a connection between physiological and bio-electrical events and the process of positive psychological control (Wickramarabera, 1976; Shapiro, 1979).

Kreiger (1979) is one of the nurses pioneering a technique of healing known as therapeutic touch. The technique described as an act of healing that is akin to the ancient practice of laying-on hands, has been demonstrated as a useful adjunct to orthodox nursing. Basic to therapeutic touch is the concept that the human body has an excess of energy. Studies indicate that the transfer of energy that is presumed to occur in the process appears to be done physiologically by a kind of electron transfer resonance. EEG monitoring during this process shows a predominant rapid synchronous beta in Krieger's EEG which is interpreted as the physiological energy transfer of therapeutic touch. Although this work is preliminary in investigation, and has not been subjected to extensive experimental trials, there does appear to be evidence of an energy related component to health.

The rationale for the effect of psychological stress on energy comes from the knowledge that stimulation of the sympathetic nervous system, as during emotional excitement, increases cellular activity by the release of the hormone epinephrine, which acts directly to cause glycogenolysis and an increased basal metabolic rate (Krause & Mahan, 1979).

Krause and Mahan (1979) found that during highly emotional states, the physical activity of restlessness, muscle tension and aggravated motion of the body resulted in energy expenditure. Energy is defined as the realized state of potentialities, the capacity of acting, operating or producing an effect (School of Nursing, University of Manitoba, 1979). Decision making, a process that involves movement toward a goal is then an energy utilizing process. The decision making process may have occurred the way that families preferred. In contrast, families may have felt obstructed in participating in decisions or felt pressured to participate. Maddi (1968) described any degree and kind of discrepancy between expectations, thoughts, and perceptions as a source of emotional discomfort. Therefore, discrepancies in decision making preferences may be emotionally stressful. According to Selye (1965), when the stress state occurs, there is an increased energy demand. Any incongruence in the decision making process is reasoned to involve more energy use. How then does this energy involving process relate to the health of an individual or family? The interaction of all

family members brings many sources of energy and energy exchanges to the situation. How is energy used in these interactions? Who makes the decisions and what effect does this energy involving process have on individuals in the family and the family as a unit? That Man is an energy unit is not debated, but rather the specific nature of the unit of energy remains to be defined (Byrne & Thompson, 1973). The concept of energy is an abstraction and as such cannot be pinpointed in concrete terms. An understanding of the way that energy is utilized within man, the ways energy is replenished and the energy exchanges that occur in physiological and psychological processes is as yet, incomplete. Energy is a concept that is theoretically supported from the knowledge of the function of adenosine triphosphate in the human body, cellular activity, metabolic life processes, human activity, cyclical biological changes and observations of life and death. Therefore, energy can be considered to be an implicit mediating variable that relates the work of decision making to the notion, health.

2.9 CONCLUSION

The review of literature indicated that almost all of the research was descriptive, involving participant, and non-participant observation as well as interviewing approaches. The methodological difficulties of studies related to life-death decisions include the ethical considerations of study-

ing individuals in a process that is stressful and deeply personal. Questions also arise as to the accessibility of information that is stress-laden, retrospective, and to a large extent, an internal process or a process difficult to observe or articulate. After a review of these studies, it appeared that at this time not enough has been learned about decision making related to life-death decisions to move beyond the descriptive stage of research. It also appears that in spite of the methodological problems inherent in this type of study, an understanding of this problem could be furthered in an ethically sensitive manner.

Chapter III
RESEARCH DESIGN

3.1 INTRODUCTION

The target population was identified as families living in Manitoba. In view of the lack of research related to families' perceptions of the effects of involvement in terminal care decisions, the study was at the descriptive level of inquiry. The purpose of the study was to describe families' perceptions of their preferred and actual involvement in terminal care decisions and perceptions of the effects of the degree of congruence between these two variables. The impact of the congruence was considered at the time of the decision making process and at an interval after the death of the terminally ill family member.

The major variable in this study was the congruence between preferred and actual involvement in decision making. A second variable of importance was the environment in which the decision making occurred. Glaser and Strauss' (1968) research in this area had indicated that where a person dies is significant in terms of who is involved and who controls the decisions related to the care of the patient. How this decision was arrived at by those involved, was also part of the question addressed in this study. Therefore, this vari-


able was used as an appropriate way of accessing the range and depth of data sought.

3.2 SUBJECTS

3.2.1 Target Population

The target population was identified as families living in Manitoba who had experienced the death of a family member due to cancer in the past twelve months. The majority of families were interviewed between four and six months after the patient's death (Appendix A). The literature related to the length of bereavement time varies. Manifest signs of bereavement disappear in a matter of months, but occult bereavement can continue throughout the remainder of life (Weisman, 1979). The literature does indicate, however, that the work of resolving a loss of a person takes a year or more and as the individual moves through the grieving process, a more realistic memory of events and attributes of the lost person occurs (Engel, 1964; Lindemann, 1944). Therefore, the decision as to the time of the interviews seemed appropriate based upon the available literature.

The families were those in which there was a surviving spouse in all but one case. The rationale for selecting families with a surviving spouse came from the literature related to the effects of illness and death on a surviving spouse (Shubin, 1978; Grolnick, 1972; Degrange, 1982). The marital relationship has been described as particularly sen-



sitive to the loss of one partner. This dyad is a system that reflects the response of a process in a family and provided a structural definition of the probable interaction between the surviving members and the deceased.

3.2.2 The Sample

The study subjects were selected through a theoretical, nonprobability purposive sampling technique. The most important aspect of this type of sampling is that "the events or instances recorded attempt to cover the range of the phenomenon so that the resulting concepts are as rich - full of meaning - as can be" (Diers, 1979, p. 110). In this study, sample selection was based upon the nature of the setting where the individual died. This variable provided an indicator for judging variation in the congruence families experienced between their preferred and actual participation in care decisions.

Families whose relative died at home were presumed to have had input into that decision. The home setting physically limits interference from health professionals and allows more control for families in care planning and decisions. It was considered likely that those families who preferred more control in decisions would select this setting for their ill family member. This group was also thought to be high in congruence between preferred and actual participation.

In instances where the patient died on a general medical ward in an acute care hospital, there would be more input from health care providers and more institutional control over the process of dying. Therefore, families whose ill family member died on such a ward were considered possibly less involved in decision making, which could have been congruent with their preferred involvement as well. It was also likely that there would be families who preferred active participation in decision making and whose relative died on an acute general ward where they had little input into decisions. This data provided an important description of the factors in that setting that contributed to congruence and the effects of this on families.

St. Boniface General Hospital was selected as the institution to facilitate sample selection because it has the only palliative care program in Winnipeg. The program provided families with resources, support and facilities to care for the patient either at home or in the hospital. The philosophy of the program allows a participatory approach to care decisions. One of the program's objectives is "to involve the patient and family in treatment planning and decision making so as to maximize independence and self-respect" (Palliative Care Program, St. Boniface General Hospital, 1982). Therefore, the opportunity for the individual to die at home with support from this program was an effective way of obtaining a sample of families who theoretically would have a fair degree of control over terminal care decisions.

The final study sample included ten families or sixty individuals. The ages of the individuals interviewed ranged from thirteen to seventy years. (Summary of ages and sex distribution - Appendix B). The families varied in ethnic background and religious affiliations (Appendices C and D). Although the sample could not be said to be representative of a larger population, it was interesting to note that the sample included families with a range of demographic characteristics.

Of the families invited to participate, only one family refused. This was an elderly blind widow who said she preferred not to discuss her husband's illness. All other families contacted readily agreed to be interviewed and two mentioned that it "might actually be good to talk about it".

The extent to which the interviews included a number of family members depended upon the surviving spouse contacted. In two cases the spouse felt that they were the main person involved and therefore, should be interviewed alone. In two families the spouse felt certain others would not be helpful participants to the interview which they related to family conflict between the spouse and other members. In one case, a significant family member lived a distance away so that the interview could not include that person. In all other instances, spouses identified and invited those individuals to participate that they recognized as significantly involved in the decision making process.

3.3 DATA COLLECTION TECHNIQUE

The data collection technique included: (a) an open-ended, semi-structured, face-to-face interview, and (b) field notes. The interview was tape recorded to permit as accurate as possible a recall of the information obtained. The face-to-face interview is appropriate in obtaining data that is sensitive or personal (Polit & Hungler, 1978). Open-ended questions allowed subjects to respond in their own words. This method permitted an opportunity to obtain information that was not pre-conceived by the researcher and generated rich data.

The drafted interview guide (Appendix E), was pre-tested with two families known to the researcher. The rationale for this choice was to capitalize on the nature of the relationship between the families and the interviewer to obtain feedback from respondents regarding their feelings and reactions to the instrument, as the respondents would know the researcher. The sensitive nature of the study necessitated rigorous attention to the instrument so that useful data could be obtained with regard for the feelings of the subjects.

One pre-test was conducted in the home of the family and was tape-recorded. The second pre-test was conducted at the University of Manitoba, School of Nursing and was videotaped. The family member interviewed agreed to the procedure but admitted afterward that they felt rather nervous and

self-conscious in the situation. The room was also described as rather cold and clinical. Both tapes were reviewed and it was judged that the visual quality of the second pre-test was not significantly more helpful to continue the interviews in this way. The non-verbal gestures captured on visual tape were minimal. It was decided that the interactional and non-verbal components of the interviews could be captured accurately through field notes and that interviews in the more "natural" home environment were more important to the validity of the data. Therefore, it was decided to conduct the interviews in the homes of the families using a tape-recorded interview technique.

Field notes were made immediately following the interview to capture the non-verbal behavior observed during the interview. Field notes allow observers a means of synthesizing and understanding the data that might not otherwise be achieved with only recorded verbal information (Polit & Hungler, 1978).

Information related to demographic factors (age, sex, marital status) were obtained through available records at the time of sample selection wherever possible. The information was otherwise obtained at the time of interview through a quick sketch of the family tree. This included names, ages, some occupations and marital relationships of family members. This provided an informal and personal way of quickly obtaining a demographic "picture" of the family.

3.4 DATA ANALYSIS TECHNIQUE

Content analysis was the method of data analysis used. "This method is objective, systematic and useful for handling qualitative descriptions of communication" (Polit & Hungler, 1978, p. 379). Categories for classifying the content were not pre-conceived, but emerged through the analysis of the interviews. In a factor-searching study, data analysis goes on concurrently with data collection and processing until categories evolve which encompass all the data (Diers, 1979). As data analysis occurred, preliminary concepts and themes surfaced that were focused upon in subsequent interviews. In this way, concepts and categories were enriched, verified or not supported.

Interviews and field notes were reviewed and themes were identified and noted in the margins of the recorded data. The unit of content that captured a theme was sometimes a word, paragraph, sentence or incident. Therefore, analysis of content did not focus on the length of a unit.

The interviews were transcribed and reviewed in detail to identify phrases, examples and descriptions that reflected themes. From this analysis, six categories were identified that captured six main themes in the data. These categories were:

1. Decision Control: which referred to the control over decisions defined by who had the majority of decision authority and the setting within which this decision making occurred.

2. Information: used as a basis for terminal care decisions.
3. The Meaning of the Situation: based upon the families' interpretations of information and their experiences.
4. Patterns and Characteristics of Family Interaction related to terminal care decisions.
5. Planning for Death: which involved events, experiences, and decisions related to preparing for the patient's death.
6. Effects of the Terminal Care Process on Survivors: The effects were described in response to two properties. The first being the effects of the congruence families perceived between their preferred and actual decision control. The second way in which effects of the terminal care process were described were in relation to the loss of the family member.

Each category encompassed a group of properties and characteristics related to the experiences described by families. The properties under each category reflected variations in the qualities of the themes. Whenever possible, the names of the categories and properties were the phrases used by the participants in the study. For example, the property defined as "Hope" was taken simply from repeated descriptions of this factor by families. The data was coded in the margin using phrases or notes that captured the mean-

ing of the incident. At the end of all of the data collection the coding was reviewed in total and incidents and pieces of data were compared and analyzed to identify common themes, or categories that described the data most thoroughly. The goal in this type of data analysis is to provide as accurate as possible a description of the data that leaves very few unexplained exceptions and which accounts for the majority of the variability in the field being studied (Degner et al., 1981).

The interviews were coded first by the researcher and were independently reviewed by the research advisor. Categories and properties were then discussed and compared to achieve consensus. Any incidents which were not sufficiently clear examples of the particular category or property were either discarded or reclassified. The categories and properties were then formally defined to clarify the intent of the category name and to ensure that data "fit" appropriately into the theoretical framework. Defining the categories and properties was also helpful in confirming and re-working the organization of properties and categories. Unlike quantitative analysis, the constant comparative method is not designed to guarantee that two analysts working independently with the same data will achieve the same results (Degner et al., 1981). Rather, the purpose of this type of study is to describe accurately and comprehensively the range and depth of data obtained.

3.5 VALIDITY AND RELIABILITY

The purpose of the study was to describe the parts of the problem. Therefore, the study was a factor-searching one. The concerns about validity and reliability in this type of study are different than for studies at other levels of inquiry (Diers, 1979). In this type of study, formal instruments such as questionnaires or psychological tests are often not used. Therefore, the usual tests of reliability and validity used in quantitative research do not apply (Glaser & Strauss, 1967). In qualitative research such as this, the purpose of the study is to generate theory, not to prove it. Therefore, reliability and validity are concerned with the thoroughness and range of data obtained and the credibility of the theoretical framework that arises from the data analysis process.

Internal validity of the interview process was addressed by obtaining face validity of the interview schedule from nursing experts. This was done by asking nurse researchers if the interview schedule would, in their opinion access the concepts that the investigator wished to study. The interview schedule was developed after a review of the literature and was employed after a study of sound interviewing techniques. A pre-test of the interview schedule also allowed the interviewer to identify whether or not respondents were able to articulate the information sought.

External validity refers to the extent to which the method of data collection provides data compatible with other relevant evidence. This type of validity is considered in the discussion of the theoretical framework that emerged in the context of related research findings in the literature. Components of the theoretical framework were documented in the literature. However, other research findings had not described the components of the theoretical framework in total, or in this particular way.

A discussion of validity in this type of research must address the four requisite properties of qualitative research described by Glaser and Strauss (1967). The first requisite property is that the theoretical framework must closely fit the substantive area in which it will be used. Second, it must be readily understandable by laymen concerned with the area. Third, it must be sufficiently general to be applicable to a multitude of diverse daily situations within the substantive area, not to just a specific type of situation. Fourth, it must allow the user partial control over the structure and process of daily situations as they change through time.

The integrated theoretical framework, the density of data obtained, and the effort to maximize the range of data collected using a theoretical sampling technique support the validity of the study. The final validity test will be the extent to which the theoretical framework is a useful guide



for clinicians and researchers in the substantive area of terminal care.

The issue of reliability in this type of study is concerned with the reliability of the sources of data and of the recorder. That is, the sources of data should well represent the developing concepts and the researcher should be able to record all the data obtained (Diers, 1979).

The researcher attempted to address these concerns in a number of ways. It is believed that the reliability of the study was increased by obtaining data from more than one family member. This prevented generalizing to all family members on the basis of one member's response. It also decreased the problem of recall of events that would have been more significant if only one person was interviewed.

In terms of the reliability of the recorder, only one person, the researcher, was involved in the data collection. Therefore, a relatively consistent approach was used in interviewing families. The interviews were tape-recorded which provided a reliable method of retrieving the information. The researcher also used reflective statements to ensure the accuracy of hearing statements made by participants. In this way, families could agree or disagree with the reflected statements of the interviewer, which would clarify and confirm the statements.

The researcher observed that participants did try to make data more accessible to the interviewer in some cases. Par-

ticipants would explain their reasoning behind a decision or their responses to a decision because they knew this data was of interest to the researcher. Therefore, the process of data collection may have sensitized some participants to the issues discussed. The degree to which this affected the reliability of the data is unknown.

3.6 PROTECTION OF RIGHTS OF SUBJECTS

The protection of individual rights in the research was addressed by obtaining informed consent to participate in the study. This was obtained by providing the subjects with a consent form outlining: (a) the purpose of the study, (b) the voluntary nature of participation, (c) assurance of confidentiality, (d) the acceptability of withdrawing from the study at any time, and (e) the availability of the results to respondents if they so desired (Appendix F).

The element of concern was the issue of the degree of risk to subjects as a result of participation. "Risk" can be considered as the possibility of psychological injury as well as physical and social injury that may occur as a result of participation (Diers, 1978). The psychological risk factor was explored in discussions with colleagues. The literature was also reviewed with this element in mind. It was believed that the degree of risk was considerably less than the value of the knowledge that might be obtained from such a study for the benefit of families and patients in similar

situations. The subjects were assured in writing that the tape-recordings would be reviewed by the researcher and advisors only. After the study was completed these tapes were destroyed. Pseudonyms were used in reporting incidents from the interviews.

3.7 LIMITATIONS OF THE STUDY

The study was limited in that the findings cannot be generalized to a larger population. This is true of purposive samples and is acceptable if findings are not interpreted as representative of the target population (Williamson, 1981). The sample size was of a sufficient size to generate rich data because of the deliberate theoretical sampling. It was expected that the numbers of families that represented high and low congruence participators would be imbalanced. The investigator accepted this at the outset, as the intent was not to correlate or compare groups, but to access the range and depth of data within the various contexts. It was also acknowledged that while setting may not be the best indicator variable of congruence available, it appeared to be a theoretically sound and accessible indicator for selecting families who had experienced a range of degree of congruence between preferred and actual participation in decision making.

The validity and reliability of the data were dependent upon the accessibility of this type of personal information

from the respondents. Therefore, the interviewing skills employed were a key element in determining the richness of data obtained. The theoretical framework presented within the findings based on the constant comparative form of data analysis is one way of describing the terminal care decision making experiences of families. The researcher is confident that the theoretical framework is thorough and accurately describes the actual experiences described by families. Some hypotheses emerged about the relationship of these categories, properties, and characteristics of the theoretical framework. These remain to be researched and tested further.

3.8 SUMMARY

where the study was done

A theoretical framework that described families' perceptions of their involvement in terminal care decisions was formulated. This was done on the basis of collection and analysis of interviews and field notes obtained from in-depth interviews of families who had experienced the death of a family member within the past year. Data were collected from families who had experienced the death of a family member at home and from families whose family member had died on an acute medical ward of a general hospital. Data were analyzed using a method of content analysis called constant comparative analysis. This method is appropriate for analyzing qualitative data and resulted in a descriptive theoretical framework which encompassed the experiences families described.

Chapter IV

THE FINDINGS - DECISION CONTROL

4.1 INTRODUCTION

Control over decisions emerged as an important issue in the terminal care experience reported by families. Decision control was the power over choices made related to the care of the terminally ill person. The decisions were those that the family was aware of from the time of the occurrence of the patient's first symptoms until his/her death. The control over these decisions varied according to who was involved in the process. Three types of decision control were identified: (a) medically controlled decisions, (b) family controlled decisions, and (c) nursing controlled decisions. The determination of who was involved in the decisions was associated with the location in which the care primarily occurred. The settings within which decisions most commonly occurred were the hospital and the patient's home. There were also decisions about when and why the patient would move from one setting to another. The notion of power and authority was identified as significant to control of decisions. This use of power was evident in the methods that individuals in these situations used to gain or maintain control over decisions.

4.2 MEDICALLY CONTROLLED DECISIONS

Medically controlled decisions were those decisions related to the care of the terminally ill person that were made by the physician or team of physicians. The control of decisions by physicians was more evident when the patient was in the hospital or was frequently admitted to hospital for treatment and care. For example, one family member described the patient's passive role in decision making once she was admitted to hospital: "Once she was in the hospital she never refused."

Medically controlled decisions were more common when results of laboratory tests and knowledge of available medical interventions were important to the decision. Physicians had control as they were expected to order tests and interpret results to provide the background rationale for their decisions. Families were trusting of the physician's judgments in these instances and relied on their decisions and conclusions.

Daughter- Well she went in for weeks and weeks of tests, x-rays and stuff. And then they were deciding what to do. They had someone look at her down below (at her uterus) and see if they were related, the breast cancer and the lower part cancer, and they wanted to know so much before they actually did anything. So they sent her home. She was home a couple of weeks...

Interviewer - After they'd done all the tests, before they made a decision?

Daughter- Yes. Then she went back in to have the actual hysterectomy.

Interviewer- Who made that decisions, do you know?

Husband - The doctor said she needed a hysterectomy.

Decisions to initiate treatment interventions and to discontinue treatments were also medically controlled. Families in these situations accepted medical decisions to initiate or discontinue treatments as these decisions were often based upon the physician's opinion as to whether or not the intervention would help.

Interviewer- Who decided that she would have the operation?

Husband- Dr.M. or Dr.V. And they cut her off medication, the needles, what do you call the needles for cancer?

Interviewer- Chemotherapy?

Husband- Yes.

Interviewer- Did she have chemotherapy too?

Husband - Oh yes, sure. She had pills for one year, then she had needles for two years, once a month. Then they cut her off in 1981, after the operation. They said it was no use giving her needles anymore.

Families also described situations where decisions were made by physicians when families had no preparation for the decision or little awareness that a decision had already been made.

Husband - So we thought in our own mind that she would be going through more tests and examinations and discussions about other treatments and so on. But when we sat down with the doctor he just walked in and said "so you've got the bad news, we've got your surgery scheduled for tomorrow." That was all news and a surprise to us.

I- That decision had been made before you even knew it.

Husband - Yes. So we had no time really to consider other things. At that time the questions we had of the doctor he just simply explained at that point. As far as they were concerned the best move was to have the surgery as quickly as possible. And I guess faced with limited information we had to agree fairly quickly. So that went ahead the next day.

Most medically dominated decisions occurred at the beginning of the illness episode. Families described the time from the patient's first symptoms until the beginning medical intervention as a phase during which they were often shocked by the diagnosis and were quite passive in participation in early decisions.

I- And who made the decision about that?

R- About the chemotherapy? Well, we talked it over with Dr.W. in the hospital. He told us what he was going to do and we agreed with it.

I- There was no question...

R- No question.

The passive role of the patient and family was often experienced as being caught up in a fast moving series of decisions:

Husband - Then the doctor decided he'd better do a complete series of x-rays and this is where it was really picked up.

I- On the x-ray?

H- Yes. So he immediately scheduled, as soon as he got the results of the x-rays, he scheduled a meeting for her with a surgeon. He'd lined up the surgeon already and the surgeon said, this was in August now, "I'll give you ten days to get things in order," last minute children's clothes for school and things like that, then he put her in hospital.

The time available to make decisions also affected how much discussion ensued about a plan or intervention. This was most apparent in situations where life-death decisions had to be made. These were described as emergency decisions, and physicians were dominant in these decisions.

Husband-I phoned Dr.X. to tell him what was going on, and he asked me if he should come over and I said that would be a good thing. So he came over within three quarters of an hour and ended up taking her to the hospital in an ambulance, which I thought was primarily a precaution, but as it turned out, what was happening was that she had a fluid build up around the heart and her heart had no room to beat, which is totally new to me. I didn't know that that could happen, let alone what it all meant. When they got her to the hospital she was having quite a bit of trouble breathing, they were calling doctors to come and take a look at her. And I had to take wedding pictures at a wedding that night. So I left her about three o'clock to go and take these pictures. At six I get a phone call that they're taking her in for emergency surgery for this fluid around the heart. And that kind of shook me a little bit because I wasn't prepared for it to occur at all, like that and I didn't think that whatever was going on that day was that severe.

Physicians were dominant in decisions related to treatments such as chemotherapy and radiotherapy, decisions to have surgery and plans to have tests and referrals. In these areas families said that they often did not have the information base to make these decisions and therefore, relied on physicians to direct these choices. Later in the illness, families sometimes took a more active role in these decisions as they learned more about the treatments. Some families did regret not being more active in the decisions related to these treatments:

I- Would you say you would have preferred a different kind of involvement in any decisions that were made?

R- I guess probably right at the start, if we were more informed as to what all went on. And probably, she had a fair bit of radiation treatment through the whole thing and it seemed to us that the radiation did more good than the chemotherapy treatment. And so we would have probably liked to have more discussion about one or the other or the different uses and so on. Now we certainly did understand that radiation was more of a localized treatment. But in her case everytime they used it it seemed to work for what its purpose was. So we thought it could have been used more or sooner.

Another area of medical dominance in decisions involved decisions to pursue experimental treatments. In these instances, families remember feeling desperate to "try anything" and were willing to go along with any treatment that gave some glimmer of hope even when the side effects of such treatment were seen as extreme.

Husband- What happened was she was involved with this experimental program, Dr.X. the oncologist said that they understood what was the problem with those 20% that didn't survive the treatment. And decided that she seemed to be in good health. Her blood count was good. And she was a strong person, not big physically but she had good endurance. Anyway, he thought that she would be a good candidate, she appeared to be in good shape. So he put her in this program and she had the treatment once.

Physicians were also involved in decisions to pursue interventions intended for palliative purposes. These decisions were seen by the family as important and conveyed a sense that the physician cared about the patient.

I- And who arranged that last bout of radiation?

Husband - As a matter of fact it was Dr.A. this time.

Sister- For comfort, for pain.

Husband- Well they were really pleased with the response of the tumor in the shoulder area. So what Dr.A. did, was he arranged sort of a conference with himself and Dr.B. and Dr.C. and I think Dr.A. was the one who suggested that they do radiation, but that's not his field and really had to be the others that made the decision, but it was sort of his initiation.

Sister- They were hoping to shrink the tumor that was pressing on her kidney, because that was causing so much pain on the nerve that ran down the leg.

Another theme that emerged related to physician control of decisions was the outcome of those decisions and whether or not families perceived caring from the physician. In some cases decisions were seen as bad decisions in that the outcome was detrimental to the patient. In one case, the surviving spouse described the decision for the patient to have a gastrostomy tube as primarily the doctor's decision. Both he and his wife knew very little about the procedure so they accepted the decision to proceed quite passively. Later, there were complications and the surviving husband stated that "X didn't think it was worth it. She would have been better to stay on the nasal tube." However, the physician was described as very caring and supportive and no blame was directed at the physician for what the family considered a "bad decision".

On the other hand, there were situations described where the physician was angrily blamed for the negative outcomes of medically controlled decisions. The blame was often stated with the comment that the doctor did not care.

Husband- Now what bugs me is that there's not one doctor who has the courtesy of phoning me and saying, look, we made a mistake, we're sorry, it wasn't done on purpose. They could at least apologize and say we said it was local and it wasn't. Do you think the doctors would do that? No. And that is something. If I ever see one of them I'll tell them right off the bat. That they won't get away with!

I- That's important, for doctors and nurses to acknowledge that they fell badly about what happened.

H- That part makes me feel really bad. They could have said "we made a mistake and we apologize." I would have said, "I know doctor, you did your best."

I- There was a lack of caring you felt?

H- On their part? Well at that point I wondered. Are they just there for the business or are they there to experiment and once the person's gone, what do they do, just forget it? It's pretty hard.

In summary, medically controlled decision making was the most frequently identified form of decision making when the patient spent the majority of time in hospital and when decisions were based more on technical or scientific medical knowledge. In these instances families surrendered control to physicians and relied heavily on their advice and judgments.

4.3 FAMILY CONTROLLED DECISIONS

Family controlled decisions were those choices related to the care of the terminally ill person that were made by the family, or by the family and patient. The patient and family

had more control when the patient was mainly at home for the duration of the terminal illness process. The decision about whether to be cared for at home or in the hospital was a pivotal decision to the control over care choices that followed. For example, one daughter recalled her father's feelings about his decision to be cared for at home: "He preferred to be at home where he had more control of the decisions, what he wanted."

There were also situations that involved decisions about when and why to move from one setting to another. In these decisions, called "transitional decisions", families and patients had the most control. In some cases families and patients made decisions to move from home to hospital because of the urgency of their symptoms and the perceived need for some sort of medical intervention. The most frequently cited reason for going to the hospital was pain.

Sister - She went in once more, she was in the first week of June, I think.

I- For pain control again?

Husband - Yes.

I- Who made that decision, for her to go back?

Sister - Well she did, because the pain was so bad. She wanted it...

Husband - reassessed.

There were also transitional decisions that involved movement from the hospital to home. These decisions were often related to the patient and/or family's decision to reject or discontinue a form of medical treatment.

Husband - So we had a chat with Dr.A. He said,"we decided that we shall try chemotherapy." And my wife said,"no". And Dr.A. said to her "what are you going to do?" She said, "I'm going back home and I want to die at home, I'm not going to die at this hospital."

The decision of the patient and/or family about when to seek medical attention was a very significant decision in the entire terminal care experience and was viewed as having a possible effect on the outcome of the disease.

Husband - Actually it started about ten years ago I guess, when she had a lump on her breast that she never went to see about. She refused to go to see a doctor, no matter what we said.

Daughter- I phoned doctors - they said ,"we can't drag her in here, if she doesn't want to come." And, I guess in May her stomach became swollen, she had been...

I- May of ?

D - 1982 - She'd been in pain I imagine for years, not alot, but well, she's very stubborn. But in May her stomach was swollen so badly that she went to the doctor. Then the doctor put her in the hospital. It was all really fast and really sudden.

Family controlled decisions were evident when it came to choices about the form of treatment to follow. Families reported having to decide whether or not to pursue traditional types of medical treatment or to try unconventional forms of intervention.

Husband - We had friends that were giving us alot of encouragement to pursue the natural methods of treatment and the Mexico excursion and all those things, which really tended to complicate matters a great deal and make you do alot of thinking and questioning and wondering. And also, we talked things over with Dr.X. and so on, and made our own decision that we have as much faith in Dr.X. as we would in any other method. And we felt he was as knowledgeable about the state of the art as any-

body that there was. So our decision was that whatever we did, we'd have to believe in. I think it was a joint feeling that Dr.X. was as good as we could find. The pressure that we got from some other people to pursue other forms of treatment we never really followed up. Also, after the following up that we did, we came to the conclusion that to follow any other method required tremendous discipline on the part of the patient. And in terms of diet, eating things you never wanted to eat before, Jane was not a person to become very disciplined or regimented to anything. So I think jointly we decided that although that may be a route that is accessible and may turn out someday to be an acceptable treatment, at the time, the knowledge available said that these other methods were not the approach to follow. So we stuck with medical methods.

In other cases families sought alternative treatment when they did not believe in the proposed conventional medical plan or when they were given no hope by the physicians involved.

Husband -So the doctors finally decided around September that they should operate. And Helen says, "I don't want to have an operation." Well, I said, "You don't have to it's your decision." So in the meantime I got in touch with a man who had cancer, bone cancer, who had had all the treatments, cobalt treatments. But they had to stop the treatments because he was so burnt. He was about to die. But he said I'm going to try something. He went down to Tiajuana. The clinic that uses simply a diet and juice extracted from plants. You wouldn't believe that the man had cancer. So when my wife saw him I said "do you want to go there and try it?" She said "yes," so I bought the tickets and made all the arrangements to go down.

The family and patient also exercised control in decisions about whether or not to seek alternate medical opinions and in some cases whether or not to change physicians. One surviving daughter described how the family made the decision to change doctors and the difficulty in doing so:

R- It was here in Winnipeg. Right away we wanted our doctor off the case immediately, when we saw what was happening. And he made it very difficult for us. And other doctors are reluctant to take on other patients. We went through about seventy-two hours, my Dad was in the ABC hospital. Nobody wanted to put their hands on him because we got Dr. X. off the case.

Therefore, in terms of medical treatment decisions, families exerted control by choosing the form of treatment and the physician that would care for the patient. Their control over medical treatment decisions after that was usually considerably less.

Another area that families exerted control over, concerned decisions related to who was to be informed about the diagnosis and prognosis. For example, young children and older parents were frequently protected from information about the disease. There were often a series of related decisions about how to tell families about the illness and in what stages the information should be given. Usually news about the disease was given in parts and gradual explanations were offered.

Husband-The surgery was the 19th and she was home on the 24th. At that time of year trying to break the news to people that you're faced with this is kind of a difficult task because we didn't want to ruin anybody's Christmas. Particularly, we were concerned with Anne's mother because she had lost her husband a few years earlier which was four years at the time. So we kept it from her 'til the very last, which may or may not have been a good idea, but that was our choice.

In some cases decisions to withhold information involved denial of the truth to family members. For example, one hus-

band described the interaction between himself and his daughter after she had learned of her mother's diagnosis of leukemia:

Husband- The oldest daughter went with a girlfriend and to the doctor and she asked him, "what is my mother's problem?" He said "leukemia." She came home with her girlfriend and she said to me "do you know that mother has leukemia?" I said, "the doctor doesn't know what he's talking about. These doctors don't know." The reason that I did that was so that she would learn step-by-step. Not just boom (claps hands) like that.

There were also instances where decisions were made by the family to withhold information from the patient:

I- Did anybody else know at this point that there were cancer cells in the stomach or were you the only one in the family?

Husband - One daughter knew who was with me, because she was with with me when I questioned Dr.X. I said to her, "not a word of this to your mother and not a word to the others. It's no use getting everyone more worried."

Families were also dominant in decisions related to care at home. These decisions included which family members would participate in the care, who would move in with the patient to help, and decisions to obtain home care assistance.

I- So was it your decision that you would have Home care?

Husband-I knew if she came home she couldn't use our bed because you can't raise her feet or head. So I said you need a hospital bed. And I thought the Home Care would supply it, they supplied everything we needed. They were very good.

Often, decisions about whether or not the patient would be at home or not depended on the physical resources and age

of the family. For example, one seventy year-old widow was willing to look after her husband at home with help from home care if there were hospitalization periods for her husband to give her some respite.

Wife - I couldn't keep him home all the time because I had two heart attacks and it was too much for me. When I'd get too tired and he wasn't feeling good, I'd send him back to the hospital for awhile.

The decision to care for the patient at home also reflected the families' awareness of the community resources available to them. In some cases, families knew home care was available and were quick to contact them for assistance. These families were also able to indicate to home care when they needed additional help as the patient's condition worsened. The available supports within the family also facilitated the decision to care for the patient at home. In families with many supportive family members nearby, the experience was described quite positively.

Daughter -Well the Home Care made it very easy for us. They provided people five days a week. Weekends I would be there alot with Nancy. Weekends someone from the family would fly in. There was always someone here helping. Just for moral support which I really needed at that point.

In other families decisions about organizing care at home were more difficult and families described the situation as more exhausting. As one older widow recalled: "I've got a son that lives in Alberta and a daughter that lives in Virden, so they couldn't help. I was pretty much on my own."

In families where the surviving spouse was older there were often fewer family supports and the care was described as very demanding. The siblings of older families were also older and had illness problems of their own. In these families, care became the responsibility of the elderly spouse and in some cases the children, if they lived nearby.

Other decisions controlled by patients and families concerned choices about the patient's activities at home, his ability to work, and his or her participation in social and family activities. One common decision made by families was whether or not to travel. This decision often involved logistics of organizing pain medication, wheelchairs, places to stay and access to medical attention if necessary. Problems sometimes occurred when these decisions were not clearly planned and changes in the patient's condition occurred.

For example:

Husband - When we went to Saskatoon, she seemed at that time okay, we started with 100ml. prescriptions and at that time we were getting prescriptions of three liters at a time, which was quite a massive amount. It turned out that that wasn't touching the pain. It was not too bad at first though. So we went and had been there a couple of days and then the pain really started to escalate. We had been given the name of an oncologist in Saskatoon by Dr.X. and we were to call him if any problems arose. And we did. He got the particulars from her, what she was taking and suggested we go down to the Saskatoon University Hospital and they went ahead and tried to give her a shot of Morphine and that didn't really help. I guess the next day we were going to be heading home and we'd driven down there. What we did is we tried to arrange a flight for her to come home. We were able to get a flight that afternoon. So I left with the kids by car and an uncle and aunt arranged to take Lynn to the airport. Meanwhile, I had phoned a

sister and she was going to be here at the airport and she took Lynn straight to the hospital.

It was apparent that these families had much decision making responsibility. They needed to understand the patient's condition, how to access the health care system and be familiar with treatment and medication particulars. The resourcefulness and effective problem-solving behavior of families was especially notable.

In summary, the family controlled decisions occurred more often when the patient's care took place at home. The types of decisions families had control over related to the organization of home care, the general type of treatment to pursue, control of information given within the family and decisions to do with transitions from one setting to another.

4.4 NURSING CONTROLLED DECISIONS

Nursing controlled decisions were those choices related to the care of the terminally ill person that were made by the nurse. Families described the role of the nurse in care decisions more often when the patient was cared for at home. In these families, it was the visiting nurses that were described as most actively being involved in the terminal care process. These nurses were described as very supportive and central to the care given at home, but their input into decisions took the form of "suggestions" rather than decisions. The home visiting nurse was seen as an information

provider and a resource to families in their control over decisions. Nurses rarely acted as the decision maker themselves. The only time that the nurse was described as the decision maker was when a decision was made to transfer the patient from home to the hospital when there was a deterioration in the patient's condition.

Husband-She got so that she couldn't even stand on her feet. That was the 18th of March. I just couldn't get her up, I had to lift her onto the chair to get her to the bathroom. So I called the nurse and she came and checked her legs and she didn't have anything in her legs at all.

I- No feeling?

H- No feeling, no. So the nurse told me to get an ambulance and take her to the hospital. (Tears) And let's see..I got her in that afternoon. She was fine at night and in the morning she'd gone into a coma (tears).

I- So then the decision was really made by the nurse to go to the hospital?

H- Yes that's right, yes.

I- And it turned out to be a good decision?

H- Oh yes.

In instances where the nurse made the decision to transfer the patient to the hospital the families were elderly couples who were quite passive when it came to control over decisions. In these instances there had been no prior discussion between the family and nurse as to where the patient would prefer to die. In such situations, the surviving spouse was relieved that the decision to go to the hospital had been made by the nurse.

Nursing controlled decisions were very infrequent. However, the information and support given by the nurse to the family gave them help in making their own decisions.

4.5 POWER AND AUTHORITY

Power and authority were identified as the means of control that individuals used to affect decisions. Different techniques were used to maintain or gain control over terminal care decisions. The amount of power and authority available to participants in the interaction also varied.

Families believed that physicians had the most formal power in the situation. The physician's knowledge about the disease gave him a greater measure of authority over medical intervention decisions. Physicians were also viewed as having more status and were described as using the power associated with this higher status to influence decisions. One way in which physicians used their power to effect decisions became apparent when families wanted to try unconventional forms of cancer treatment.

Husband- Dr.A. phoned to remind my wife that she was going to have an operation. She said "no, I'm not going thru with the operation." He started, you know, putting the pressure on. And well let's face it, he said, "look you can go to Tiajuana if you want to, but if something happens, we won't come running. Sure as doctors we'll try and take care of you but don't expect, we won't go out of our way if you want to go down to Tiajuana for this stupid diet treatment."

If physicians did not agree with the belief system of the families or did not support the family's decisions they were described as becoming angry with the family.

H- She was frustrated about the doctors not because she had cancer. She took that very calm. But about the decisions, about the doctors forcing her and telling her she was stupid, that's exactly the word they used.

In one instance a family had taken the patient to Texas for a treatment not recognized by the traditional medical associations. The conflict between physician and family about this decision resulted in the family changing doctors. This was one type of power that the family could exercise if they choose.

I was there with my Dad and his oncologist had come back from his holiday and he came up to me. He knew my mother had just passed away a few days before. And his comment to me was "Well was it worth it? How much did it cost you?" Well, I thought to myself. You animal! I just got hysterical there I couldn't talk with him. And we decided if this is the way he's going to treat us, and be to us, we had to find somebody else. Because we knew there were just a few months left, we had to have somebody compassionate, somebody who would talk, would listen, empathize! Not someone who would say, how much did it cost, was it worth it!!

As this incident illustrated, families sometimes perceived a physician's use of power over decision making as a lack of caring. In contrast, the physician's authority was sometimes seen as a confirming and supportive factor when the physician reinforced a family's decision. One daughter had more or less made the decision with the patient that he should not go to a nursing home but should remain at home. She related her need for physician support for this decision:

I called Dr.X. and I said, "My father is accepted at the nursing home and he doesn't want to go and I don't think he should because he's deteriorated

physically." And Dr.X. had just seen him a week or two before. And he said, "Well, the decision is your Dad's and your's. If he doesn't want to he shouldn't go." So he made us feel very good and he said, "we'll keep up the home care." He was very very supportive.

Frustration was often described by families when they could not affect decisions or actions related to decisions. In one instance there was a delay of sixteen days from the time a lump in the patient's breast was discovered until the biopsy was actually performed. The husband described his frustration and efforts he made to act on this decision:

Dr.X. decided he should have a biopsy on the other breast to make sure in fact that that was cancer, a malignancy. And it took something like sixteen days for arrangements for the biopsy. When they did it and the doctor that did it forgot to adequately identify the sample to the tested for estrogen receptors which was the primary reason for wanting to do it. So two days later they had to redo the biopsy again and get it sent for estrogen receptors. So that was actually the fourth attempt in her case.

I- fourth biopsy she'd been through...

Husband - Yes, for the same purpose. Actually the first time it was overlooked. But it was the third conscious attempt to do the biopsy for that purpose. So it became quite frustrating and that whole time of trying to get her into the hospital to have the biopsy was very very frustrating because we would phone to admitting and they would say, no we don't have anything scheduled. We'd say, we were told we were supposed to be there. In fact, one time we were told she was to go in Thursday night for the biopsy Friday morning. And just as a precaution I phoned at three o'clock on Thursday to see if it was okay to bring her and they said, we had no record of her admission. And so I phoned to the doctor who was supposed to do the surgery, when I got hold of him he said, "Oh was I supposed to do that, that's right I forgot." You know that was virtually intolerable. And even in the end I don't think we'd have got her in if I hadn't phoned admitting three or four more times

to explain the situation. And in the end it was admitting who contacted the doctor and said, do you want to get this person in? That wasn't Dr.X. He was away on holiday, it was Dr.Z. or something. We sure didn't like this guy too much. And finally the biopsy was done February 16th, which was three full weeks.

Families also felt powerless when it came to the bureaucracy of the hospital and the effect that rules and regulations had on care decisions:

Husband - The frustrating part about that ward of the hospital was that they couldn't do any active care and so when Dr.X. wanted to do chemotherapy he had to get her taken out of that ward to another one somewhere else in the hospital. Which seemed to me to be awful foolish, in terms of just moving from one room to another in order to hook up an intravenous. But anyway, we lived with that and I understand there were rules and policies. But they didn't necessarily make too much sense.

Families also experienced frustrations related to the lack of authority that they perceived the nurses to have. This was described by families who had cared for the patient at home, where the role of the nurse was more apparent. The nurse was the most frequent and most accessible health care provider for these families. However, while families appreciated the nurse's support, her lack of decision making authority was often problematic for families and delayed treatment decisions that affected the comfort of the patient.

Husband- The role of the nurse caused some frustrations; in that the VON really has no authority to do anything. She could make no decisions even though she would know and agree with what we should do, maybe in relation to medications or getting oxygen. But she always had to call the doctor for everything and that often caused delays for us in terms of getting answers or equipment or

changes. The nurses seemed to know enough, it's not that they didn't know enough, they just in effect had no authority. I could get better and quicker results by talking to the doctor myself directly.

One way in which the greater status and authority of health care providers was experienced by families involved their fear of "bothering" the physician. Families tried to make sure that they did not disturb the physicians too much and experienced some doubts about decisions whether or not to call the doctor when there were changes in the patient's condition. Decisions to call the physician were sometimes delayed because families did not want to irritate the physician if the concern might be seen by him as unimportant.

Husband - Whenever I sensed that she (the patient) was having trouble I would phone Dr.X. and get him informed as to what I was perceiving being problems. Then as it turned out everytime I did end up taking her to the hospital, or said we've got to go see Dr.X., or phoned him and said there's something different happening, that in fact there was. He and I have talked about it afterwards and I suppose to some extent he was trying to make me feel better about the whole thing too, but I was quite concerned that I was bothering him too much. And he said no, everytime you have it's been a reason.

Another theme related to power and authority over decisions involved the quality of communication between health care providers and families. In instances where communication was described as poor, physician authority was often interpreted as uncaring.

Sister - The plan was made for her to have radiation for pain. So she went to see Dr.X. He really hit a blow to her because she went in a lot of pain and he said "well you're a young woman. You've got a lot to worry about. You've got a young family.

You have to be careful not to feel sorry for yourself here." And all this kind of thing! And she was just devastated. Because it was no more made up than the man in the moon. Being a psychologist herself she was very aware of this kind of this kind of put down, really he was coming across and the fact that she was a woman didn't help too much. She fought back and he made very light of it and made fun of her. It was just a very bad experience. And she never wanted to see him again. However, she went through because you are kind of helpless. You have no other way of getting the right help. And he was the one who organized the treatment.

In contrast, there were many cases where families had good rapport with health care providers. In these situations, families relied upon the authority and judgment of health care providers and saw the use of power related decision techniques as appropriate and even supportive.

Daughter- The most important thing is to have someone you can talk to. Dr.W. was the man, Dr.B. was the man. And we also saw the other side, the doctor who neglected him. We could never talk to him on the phone he would not speak to us. But I think he was the extreme. So just to find somebody you can talk to.

Families utilized more oblique forms of power in gaining control over decisions. For example, they would try and diplomatically maneuver decisions in the direction that they preferred.

Husband: Near the end they wanted to move her back to Ward A and we diplomatically said we preferred to stay where we are. So all I said, if anybody else wants to go, take them first. We'll go if you need space, but we were quite happy with the nursing care.

Families varied in their abilities to obtain response and action from health care providers. Some families became

skilled at learning how to access the physician and obtain action. The communication techniques that families possessed, and their clarity in requesting response from health care providers were ways they exerted control over care decisions.

Husband - When it came to the doctor, every time that I absolutely had to get ahold of Dr.X., if I felt it was very important that I did get ahold of him, I did get ahold of him and he had time for me. And quite often, I would try and get ahold of him and not force the issue at all. I would say I'd like to talk to him if I can but it's not a priority. But everytime it was a priority I was able to get ahold of him.

Other families had less successful physician-family interaction and this affected their view of the experience. Communication was usually poor in these instances and families experienced frustration at not being able to convey their preferences and concerns.

Wife - I never met his doctor, never did.

Interviewer- Did you talk to the doctor on the phone?

Wife- I never did that either. I talked with the doctors that worked with him.

I- So you never talked to Dr.X.?

W- No, never. And the nurses when they'd come here they'd phone him and they'd have a hard time to talk to him.

In cases where the family felt powerless, their relationship with the health care providers was very limited. In these situations, health care providers were described collectively and their individual identities were often unknown

to the family. This occurred more frequently when the patient was hospitalized and the numbers of health care providers increased.

I- Was there one main physician involved in this, who coordinated things?

Husband - Ya, he was the cancer specialist, I forget his name. It was his assistant that we always saw but the other doctor was actually in charge.

I- But it was his assistant that you talked to most?

Daughter - Yes.

Husband - After that it was just the doctor on duty.

I- So the main people involved would have been this doctor who was the assistant to the specialist. You were in the background and the doctor's were sort of taking over in terms of directing how this would go?

Husband - Yes.

Another type of power families used was veto power. This was the authority that families had to withhold consent for treatments, refuse admission to hospital, and not attend appointments and treatments. The use of this power usually resulted in conflict between health care providers and families and sometimes led to obstruction of further care along that pathway. This technique was often used as a last resort by families when they felt pressured into a decision or when they believed their viewpoint was not respected.

The power of nurses was seen as minimal by families. Nurses were described as providers of information and in this sense facilitated the power of the families to make de-

cisions. Information was seen as the source of much decision control.

Families relied heavily on the knowledge power of the nurses they were in contact with even though these health care providers had less final authority. The authority the nurse did have was seen as validating the care families were giving the patient at home.

Husband- The nurses, they came and checked up every so often, health nurses?

I- Public health nurses?

H- Ya. They said it was 100% good the way I took care of her, the way I'd feed her and everything.

The home visiting nurse was described as having power over the amount of help families received. At times a lack of communication resulted in inadequate resources as far as the family was concerned:

I- Who made the decision to have Home Care?

Husband: We had a visit from the VON and I guess she assessed the situation and decided that we needed it.

I- Had the nurse been coming in from time to time?

H- They were supposed to have been. They weren't coming very frequently at all.

Sister- At that time they arranged a cleaning lady. They said she could have it once very two weeks.

Husband - Something like that.

S- The lady that came said we should have her twice or three times a week. (laugh)

I- She herself made that assessment.

S - Ya, but we never did get that. Maybe once a week eventually, but that was right at the end.

In summary, the amount of power and authority varied among those involved in terminal care decisions. Participants used different tactics to direct decisions the way they preferred and attempted to control the setting within which decision making would occur.

4.6 SUMMARY

The control over the decision making in terminal care situations took three forms: medically controlled decisions, family controlled decisions and nurse controlled decisions. The kinds of decisions that participants had control over differed according to their knowledge about the disease, their formal authority in the health care system, and the setting within which care took place. Physicians were described as having the formal authority and control over decisions because of their medical knowledge base. Nurses had less formal authority, but did have some power over care decisions as a result of their knowledge of health, illness and nursing care. Families had more authority when the patient was at home and quickly lost control when the patient was hospitalized. All participants used different techniques to maintain or gain control over decisions. The power that individuals had in the interaction was not evenly balanced.

Chapter V

THE FINDINGS - INFORMATION AND MEANING OF THE SITUATION

5.1 INTRODUCTION

Information was identified as a very important factor in the terminal care decision making process. Information included the facts acquired about the terminal care situation through reading, observation, discussion or hearsay and did not necessarily connote validity.

The decision making that occurred depended to an extent upon the quantity of information available to participants. The sources of information were also identified as significant to the decision efforts. The access to information also affected the amount and quality of information that was available. Participants could hold or release information to others, resulting in imbalances in decision making abilities. As well, the types of information available to participants emerged as an important aspect of the terminal care experience.

5.2 SOURCES OF INFORMATION

The primary sources of information were individuals who were seen as having facts or knowledge about the disease and the terminal care process. These persons were usually the family physician, the nurse, the oncologist, and surgeons involved in the care. The extent to which these individuals shared their information with the family was described as important. A willingness among health care providers to share information was seen as positive and helpful to families in coping with the terminal care experiences and making decisions.

Husband - Well, I think that we were quite capable of making the decisions ourselves. We got word from the doctor. He explained everything to us, you know, he didn't hold anything back from us. He was real good.

On the other hand, in cases where health care providers did not offer or share information easily, families experienced frustration and tension:

Wife - The thing is you just can't ask the doctors anything at all. They're really insulting. "You know what's wrong with him!!" That's what they'd tell you. We don't know, if we were doctors we wouldn't have to go to a doctor.

A valuable source of information identified by families was the nurse. Nurses were often contributors of information or clarified and interpreted information so that families could make decisions.

Wife- Of course the nurses that would come, the therapy nurse and other one, the home care nurse they were good. They'd tell me alot, of what was going on.

In interactions between family and health care provider, the transfer of information was sometimes two-directional. That is, a health care provider who gave information willingly also received information about the patient's condition from the family. This information tended to be detailed and thorough.

Wife - I told the nurses once I didn't like his leg, they were all swollen and there were little red spots on it. And his ankle were light brown and shiny. And she said, well if it opens let us know.

Other sources of information were family members themselves, relatives and friends. In these circumstances information ranged from scientific facts obtained about the disease to hearsay and misinformation. Often one person in a family would have the most contact with the physician and would be identified by other family members as the source of family information and acted as the "switchboard" for relaying messages to the physician.

Husband - My son Joseph had an appointment with Dr.X. (he has them quite regularly). So Dr.X. gave the message to Joseph and he wrote it down. So Joseph then brought the news home to us.

Families also relied on relatives or friends who were health care professionals to help them interpret information or clarify facts given them. This informal source of information was described as important.

There were a number of different doctors at the lake and when advised of what the condition was they said "well in a way you're lucky because it's the kind of cancer that can be treated by cutting out the tumor and putting it back together."

In some instances neighbours and friends gave information that was based on their experiences with someone else who had had the disease. They sometimes reinforced accurate information and in other cases confused families. It was notable that families recalled so much of the information that was offered them. They also placed significance on parts of the information that were particularly meaningful to them.

Husband - I phoned a woman who works with me, her husband died of cancer a year before my wife. I said, "Did it happen that your husband let's say two or three weeks before he passed away he stopped suffering?" She said, "yes". I said, "What was the cause?" She said, "They told us it's the nerves that burn up." I said, "that's all I want to know."

This information was helpful to the spouse in interpreting changes in his wife's condition. The family was then able to proceed with preparations for the patient's death.

Families also relied on written documents as sources of information. These included books, magazines, and pamphlets they could obtain about aspects of the disease. Written information was often a way of clarifying or interpreting verbal information given by health care providers.

Husband - Then he said, "John, bad news it's very serious she's very sick. It's acute now. Before it was chronic. Now it turned to acute." Acute is the fast. It was hard time for me to find out what acute meant - anyway I found it in a book.

A number of families pursued and investigated treatment considered unconventional by the established medical associations. The sources of information about these treatments were the media, such as television and magazines.

Daughter-Well we decided that the only thing to do, was go to Texas. I don't know if you've heard of Dr. Brazinsky in Texas. There was a whole big thing on television on him, alot of Canadians are going there. On March 1, there was an article in Macleans magazine and I remembered it. My brothers had seen it too.

The sources of information then, included people, written material and the media. The sources could be used to obtain facts, clarify information or to help interpret information families had received from other sources. These sources were pursued to different extents, but all families talked of the value of these sources of information and the ways they accessed these sources.

5.3 QUANTITY OF INFORMATION

The quantity of information referred to the amount of information or facts related to the terminal situation that were available to families. No family stated that they received too much information. Families either thought that they received inadequate amounts of information or were pleased with the quantity that they received, which they described as quite complete. The importance of information was evident as families discussed the positive aspects of being "well informed".

I- So the doctors were keeping her very informed and you informed about what was going on?

Husband- We knew what was going on all the time. That was a good thing because there's no use beating around the bush. What for? Some doctor tell us some story, you know. We didn't need that.

In contrast, a lack of information was described as frustrating for families. A lack of information often resulted in confusion for families and sometimes caused needless worry:

Husband - Then she started to get alot of pain on her side. And I guess that was four or five days later when they discovered that was Shingles. And Shingles we didn't know too much about and then later they started referring to it as Herpes which we knew less about, except that Herpes was something you got when you were bad. So we didn't know there was a relationship between Herpes and Shingles and that kind of stuff, nor what that was about.

The lack of information was described by a number of families as being detrimental to decision making about the patient's condition and care. In one instance, a lack of information about the deterioration of the patient's condition and the negative prognosis resulted in a family making a decision to proceed with resuscitation measures. They saw this later as a very inappropriate decision, but said that their lack of information at the time did not permit them to make an informed decision.

Another way the lack of information affected decisions were at times when the patient's death was imminent and families were not given this information clearly. Delays in calling other family members to be present at the patient's death or even decisions to stay with the patient themselves did not occur, because families reported not being told that the patient was dying.

Daughter- My brother said, if I only would have stayed another week, or if they only would have

told me, he could have arranged. He could have arranged. Because he could have taken time off to be here. So he's..

Husband- He's upset.

In some instances, the incompleteness of information resulted in confusion and distress for families. They might be told parts of information but not all the information that they needed to know in order to understand and implement care decisions. For example, one family described their experience when the patient underwent a toxic experimental drug treatment:

Husband - Methotrexate is the drug that they were using and it is extremely toxic. What they do is they have to flush this out of your system. The problem is the kidneys, it effects the kidneys apparently. And, they give you an antidote that must be taken in oral form, tablets, must be taken every forty-eight hours. And, what they did is they finished her Methotrexate treatment and within a couple of hours they gave her these tablets, she took three at a time and watched for the reaction to it and waited to see if she would gag and throw up or whatever, whether these things would stay down. Then they stayed down and they said, "okay, fine, here's the prescription for it and away you go." And I thought that was really poor in a sense of that this is so crucial that she take these every four hours without fail right thru the night you know. We had a schedule right thru the night and I set the alarm and was waking up every four hours but you know how nervous I was that she was, you know, if that alarm doesn't go off. And anyway, she survived that period and we were supposed to at the end of twenty-four hours and at the end of forty-eight hours she was supposed to go and have a blood test. Anyway, this fell on a Saturday and so we went into the hospital. Well they don't do the testing at the hospital where she's being treated. It has to be done at the ABC hospital. Then we found out that there was no one at that hospital on duty that can do this test.

Sister- The appointment had all been set up, we were supposed to just go and say your name. Of course, you're in a panic if you don't get this blood test. He said you must have this blood test on Saturday and it was for his research. Not life and death.

Husband - We understood it was life and death. We had to see that this antidote had worked.

The incomplete information that the family had about the reasons for the blood tests and the seriousness of the drug resulted in much strain for the patient and family.

In another situation, the family was given information about the palliative care ward that provided them with immediate access to a hospital bed if necessary. The information that was not given was that the ward was for terminally ill patients.

Husband - We got a call from the home care nurse one day, saying, if you need it you can come to this certain ward and nobody told us what it was and we didn't know what it was. Other than we thought it was a good deal to have access to hospital on demand, sort of. But it was a good week or ten days of her being there before I finally figured out what that ward was all about. And why in fact she was there. And nobody had told us up to that point that things were as severe as they were and that was the only reason she could get there because she was already - identified as being terminal.

The completeness of information was therefore an important aspect of the understanding families had about decisions and care. If there were gaps in explanations; confusions or needless worry resulted for patients and families as they tried to piece together what was happening to them. The amount of information available to families was very im-

portant to them. In no instance did a family say "I wish they had told us less". All families either appreciated the fact that they were informed or regretted not having more information available to them.

5.4 CONTROL AND ACCESS TO INFORMATION

Families described the regulation of information that occurred by individuals in the terminal care situation as an important factor that affected their access to facts. There appeared then, to be two forces operating when it came to information sharing. One was the control of information by those with the information and the ways that they limited release of facts. The second element was the techniques and abilities of others to secure the information. Therefore, the communication and interaction between participants was central to this issue.

Health care providers were identified most often as controllers of information. The ways that they controlled information included the ways they answered questions, the extent to which they offered explanations, the degree to which they would interpret facts and their availability to families. In some instances health care providers were described as being evasive when it came to giving information and answers to questions.

Now the thing is that they told my wife before the operation that the cancer was local and they argue the point that it was strictly local. There was nothing to fear, after they operate, they take out the womb, and that would be it. She'd be okay and

everything, so I asked Dr.X. "what did you find out?" He says, "the operation went alright." I said, "You know Dr.X. at my age you better tell me the truth. I'm not the kind of a man you fool around with. What did you find out? I'm not asking you if the operation went alright." I got a little mad. I said, "I want to know what you found while you were operating!"

Families also encountered a lack of clear information from health care providers when it came to questions about the prognosis and expected length of time to live:

Husband - It had been a very large tumor and he said the prognosis was not good. Then I remember my wife asked him what does that mean, how much time have I got or whatever. And he sort of evaded the question by saying what the situation is. He said I've seen people with worse conditions than your's and they've carried on for some time, and I've seen others whose condition is much better than your's and who went very quickly. That was what he said.

The sharing of information by health care providers with families facilitated a trust in this relationship. This was described as important when emergency decisions had to be made and the consent of families was not possible.

Husband- And in terms of some of the other decisions, I think that the doctor kept us fairly well informed as to what he was planning on doing and so on. And I guess in fact, some of the things at the end, like when she was taken for emergency surgery; that was done without my consent actually, and I don't know whether Anne had signed a consent form or what. But Dr.X. just felt from what we had talked about that I knew that would be okay anyway. He was right, it was okay. I think we had developed a mutual trust.

Families also controlled access of information to each other. In some instances, one family member had the main contact with the physician and was then the source of infor-

mation. The degree to which this person chose to protect others from the "news" effected the information available to other family members. For example, in one particular family there was a language barrier between the physician and family. The patient's husband understood more English than the patient; therefore, he was able to keep her from knowing her diagnosis for the five years that she had leukemia.

Husband - Dr.X. says straight "you have achronic leukemia, it's not like the movies," he says. Just like that. But it's very serious. That type of disease, most of the time five years, maybe a little bit longer. It depends on how fast it go. Anyway, I says to the doctor, "it's possible to hide from her?" He said "No, I have to tell her." Anyway my wife has the problem to not understand very well the language. Which was just perfect for me. Because I give you my reasons. Now some Greek, it is a Greek philosophy to hide to the patient, they are not strong enough as they are 100%, it is hard for the personality. So I hide from her.

There was a cultural belief in this family that the patient should be protected from the knowledge of her disease. For this family the decision to not tell the patient the diagnosis was seen as the right one.

The extent to which families knew the facts about the patient's terminal illness depended to a large extent on their ability to ask questions and whether or not they knew what questions to ask. In some situations, the fact that families did not ask questions left them very unaware of what to expect and they felt guilty later that they had not known what was going on.

Daughter - And I don't know if my father and I are both just too quiet and don't ask enough questions, but we were not aware that she would -

that the cancer was that bad that she would die. Right to the end we didn't know that, because, it was a shock.

In other instances, families were very assertive and clear about the questions they had and the answers they sought. For example, one patient had lost her ability to speak. She would write down her questions for the doctor and the patient's husband would deliver the list of questions and concerns to the doctor before her appointment with him. Then, when she attended the appointment he was prepared to answer her questions and all participants felt satisfied with the interaction and the use of time.

In summary, the control and access of information was an interactional process that involved the communication skills and motives of those involved. The process was not described as always clear and smooth and there were a number of ways in which the movement of information could be affected.

5.5 THE "FORMS" OF INFORMATION

The information that was communicated between participants varied in the kinds of facts that were available to families about the terminal care situation and the ways in which these facts were presented. Information was sometimes given in a direct, "cut and dried" way that permitted clarity for families as to what was happening.

Husband- Everybody knew what she had from the beginning. Dr.X., he tells it like it is. He's a good man. He told us, her too. We knew what was cooking, you know, how bad it was.

In other situations, families described a number of more subtle ways in which they were told about the diagnosis or the severity of the disease. These same families said that they did not know that the patient's condition was that critical.

Daughter- Dr.X. came in and he told us why, like they could put a tube down and suction? Suction it, because she couldn't clear it anymore, the fluid in her lungs. And he said there should be no problem, they could clear it out. And the second time they told us to leave and she died.

This incident demonstrated how information intended to be soothing or gentle could be so vague that the family did not understand what was actually occurring. Families described words such as "stabilize" or phrases such as "slow down the cancer", or the fact that "there were things they could try", as ambiguous statements that gave them hope, sometimes false hope. One such instance occurred with a thirty- seven year old woman who had breast cancer and extensive metastasis:

Husband - I went down there and spent a few hours with her as she went through two or three of these seizures. I had never seen a person seizure before. And they were quite severe. But then that led to more brain scans and things like that and radiation on her head. And she was starting to lose her hair and then she got confused again. And at that point it was about the last week when Dr.X. had to be away and he had really said at that point that there was nothing more that he could do. We could just hope and wait that she could settle down and stabilize for awhile, even in the condition she was in before they could do anything else. Some of the other resident doctors were trying to tell me that there was no hope.

The patient died a week later and the husband recalled how he held on to Dr.X.'s words at the time, wanting to believe that there was still hope of recovery or at least more time with the patient. When the patient did die he described it as a "shock".

Information could also be given in technical medical language that had little meaning for the family. Families would often not question the information given because they did not really understand what had been said to them. As a result, clarification of facts through a two-way dialogue did not occur. Families would go home hoping to find out from another source what the health care provider meant.

Husband - Our doctor didn't say anything. Just, "I want you to go and see Dr.X. at the oncology unit." So that's the first time we heard of that, we didn't even know what oncology meant at that time. We found out later on.

The specificity of information given varied. Some information involved descriptions of the diagnosis, the prognosis and availability of treatment. This information was given usually by physicians. Other types of information included ways to care for the patient, how to obtain home care, the interpretations of symptoms, and expected side effects of drugs and treatments. This type of information generally came from nurses and friends and relatives in the patient's support network. It was often this detailed type of information that was described as important to the families' ability to cope and the day-by-day physical and psychological comfort of the patient.

Husband - You see we had these charts on the wall and the VON, she used to come every day and check. And the charts of the medication she had to take were on the wall, and if there was something we couldn't handle we phoned the VON and she'd come right away.

The family described this detailed type of information and guidance as helpful to the daily care of the patient. This type of information was especially useful when the patient was cared for in the home. However, the information available to these families ranged from detailed advice about care to general vague comments about the patient's condition.

5.6 SUMMARY

The information exchange that occurred in the terminal illness process was described as central to participation in decision making and affected who controlled decisions. Those with more information were seen as having more power over the plans and choices made. There were a number of sources of information identified and participants used approaches to attempt to access facts. The success that families experienced in obtaining information was described in relation to the quality of interaction between health care providers and themselves. The quantity of information available was often stated as inadequate. Also, the form in which information was given to families was important and was most useful when it was specific, unambiguous and thorough.

5.7 THE MEANING OF THE SITUATION

One category of responses that emerged in the research was the meaning of the situation as perceived by families. This theme was identified as the families' interpretations of the information and experiences. The interpretations resulted from a synthesis and understanding of the facts, the significance they placed on the information, and previous related experiences. One element that fell into this theme and contributed to the meaning of the situation for families was their own definition of health, illness and disease labels. These personal definitions were central to their beliefs about health and illness.

5.7.1 Definitions of Health and Illness

The definitions of health and illness were the characteristics and boundaries that families used to classify a person's state of well-being or disease. A common way that health and illness were described were in terms of the activity level of the patient and their ability to function in their normal roles. For example, one patient had had a lump in her breast for ten years and she refused to seek medical attention. Her family described her as very "healthy" during those ten years:

Husband - Oh, she was in such good health.

Daughter - She never, bright and early in the morning, never see her sit there and not feel good. Everyday she'd be on the go. And she'd walk for miles. She'd walk down and take the bus. To me she didn't seem sick. She seemed very healthy.

Families also responded to disease symptoms from their own personal definitions of health and illness. As a result, symptoms were often ignored and medical attention was delayed. One component of illness for families that related to whether or not symptoms were seen as serious or illness-related was the extent of pain present. In situations where patients experienced no pain, a decision to seek intervention was often delayed.

I- There was a period of time where there was about a month's delay before you went to the doctor in the first place. What was happening then? Were you thinking it's nothing, or...

Husband - We discovered it one night and went to sleep and got up the next day and neither one of us remembered. Then it was about ten days later when we rediscovered the lump and said "Oh ya, we forgot about that", and then it went about another week when I finally said "Did you make an appointment with the doctor to see about that lump?" So that's how it went. It was a matter of us knowing it was there and never becoming concerned about it. It wasn't being pushed aside purposely or anything else. It was just something, you know, there was no pain, Mary couldn't tell it was there in any other way, except when I found it - it wasn't a conscious decision not to go and see the doctor. It was just forgotten. Had it been painful at all, she'd have gone right away.

In other cases, patients would sometimes tolerate inconvenience due to symptoms or discomfort over a lengthy time period before deciding that they were unhealthy and should seek medical care.

Daughter- They took scans and then they saw with the bone scan, it had infiltrated everywhere and the source was the prostate, which, even at the cancer institute they told us that it probably could have been avoided. He probably had the cancer for many many years.

I- And he never had any symptoms?

D- Never any symptoms, well, maybe he did have trouble urinating or, well he used to run to urinate every hour, half hour, but he never complained.

Decisions to seek medical help came usually when, according to the families' criteria the patient was ill. This often meant that the patient's ability to function had been altered. In a number of cases, the patient's bowel function had become obstructed and hospitalization was necessary. Symptoms such as extensive weight loss, uterine bleeding, detected lumps, persistent coughs, and urinary frequency were not identified as deviations from health and cause for medical attention. Therefore, the significance of the patient's and family's definitions of health and illness were central to health care treatment and decisions.

5.7.2 Reactions to Facts and Events

Families' responses to information and events in the terminal care experience varied according to their interpretations of the facts. Often information would be given to families and the meaning they would attach to the fact would be inaccurate. This was the case in one family when the patient and spouse were told the findings of the surgery.

Husband - It was about a five day wait before we got the actual words from the surgeon as to what the actual biopsy was. He said, "fortunately all the nodes that he'd removed, everyone of them was infected."

The family interpreted this information as "good news" thinking that the cancer had all been removed, when in fact the surgeon had also said that visually he could see that "the cancer had spread throughout the system".

The family also reacted to and made meaning out of comments and reactions of others. In one situation the forty-year old patient and spouse had gone to see the physician and related the following exchange:

Husband - I remember Barbara went back next week to the family doctor and she pointed out that there were already lumps around the neck area and I remember being with her and the G.P. looked at her and he just sort of shook his head and said "you're so young." Right away, you know what the situation is.

The sensitivity to the interpretations and responses of others affected the family's interpretations and reactions to the situation. Families also attached great meaning to "turning points" or events in the illness episode that prompted their awareness of the seriousness of the patient's condition. For example, one family remembered being told the patient had "three days to live". This prompted a number of decisions related to funeral arrangements and notification of family members.

Husband - And then, the last Christmas we had her in the hospital and they only gave her three days to live and she lived a year. But we had everybody in then, she came right back.

The reasons why the patient was given "three days to live" were not clear to the family. Their understanding of why the patient lived a year after that time was also incom-

plete. However, the statement that was made to them was a turning point for the family in recognizing the severity of the patient's illness and gave them some preparation for her eventual death.

The reactions to events also included responses to knowledge of the diagnosis. Most families used the word "shock" in hearing the diagnosis and prognosis. Reactions included disbelief and words such as "unreal" and "tragedy". These responses often included descriptions of the incongruence between the patient's healthy state of being and their personal characteristics.

Daughter - Dad was working, he was alert, had a business up until last Christmas time. He was running a business and he was actually doing physical labour at eighty-five. I mean he was an amazing person, this was a tremendous shock.

The shock and disbelief that families described at the early stages of the disease when they learned of the diagnosis coincided with a passive decision making role for the family at this point. Later they became more active, but initially were carried along with the plans and treatment that the doctor usually initiated. One surviving spouse recalled his wife's reaction to the diagnosis:

Husband - She didn't say much until Robert left. Then she went hysterical for about five minutes. She said, "I don't want to die - what can I do?" She was going sort of mad, like she wanted to tear everything apart. But then she calmed down.

The reactions to the disease were very important aspects of the experience. It was noted that information could be

heard, misunderstood, or not heard. The early diagnostic stage of the disease seemed to be a particularly crucial time when significant interpretations of information occurred.

5.7.3 Identification of the Situation as Terminal

The meaning of the terminal care experience was especially evident at the point when the family labelled the disease and the prognosis of the disease as incurable. Knowledge of the disease itself or the diagnosis was not synonymous with an incurable prognosis. The way in which this information was given to the family varied. In some cases this message was given very indirectly. At other times it was given repeatedly in different forms or in a forthright and clear way. The time at which families labelled the patient's disease course as terminal did not always coincide with the delivery of that message by health care providers. However, the more directly the message was given, the more clearly families themselves applied the label of terminally ill to the patient.

Daughter- To myself I realized that she was going to die, and I asked the doctor and he said they can't, they can't give or put a time limit on anybody's life. Well I didn't want a time limit. I just wanted him to say to me "Your mother is not well. She is, you know, she is not going to get better."

The definition of the situation as terminal did not always occur at the same time for all family members. Often

the patient had a more open sense of the finality of the disease than the family. The identification of the situation as terminal was influenced by the families' view of the appropriate length of time that they believed people lived with cancer. One surviving daughter stated:

She never thought she was going to die, she had so much hope and the last week or two she was slipping in and out of consciousness. At one point, yes as a matter-of-fact, at one point she said "I'm dying." We said, "Oh come on Ma, you're not dying." She said, "No, I'm dying and I want a graveside service." So I sort of remembered that, but I thought she's going to get better, she's not dying. In a year or two but not now. And she always said, "with cancer you don't die so fast, you have to struggle. You suffer and struggle for a long time."

Families also observed the attitudes and approaches of health care providers and made interpretations of the seriousness of the patient's condition. If the behaviors they observed were not consistent with their definition of care for a terminally ill person, they might not label the situation as hopeless.

Daughter - To me, in my mind, it's like they looked after her, they pushed us aside, we'll look after her, I remember that's the feeling I had then and I have now. Not that I knew she was going to die, but the... and that's another reason why I didn't think anything was too seriously wrong, no special attention to her. Just another patient. You know, you feel that, I always thought that if somebody was going to die, the doctor would maybe say, you know give her a little more attention or you know, treat her special. But there was nothing. Just go to the hospital, doctors would come in and look at her, they'd say "things are good today, things are looking good."

The family's understanding about whether the patient was considered curable or not depended on the meaning families gave to the medical treatment interventions. In some cases the interventions were for palliative purposes according to the physicians, but families interpreted these aggressive treatment efforts as indicators of hope for recovery. For example, one forty-year old woman had been told that the bowel cancer had metastasized throughout the abdomen and had spread to the neck, lymph glands and spine. She was advised that no chemotherapy was available to her. Her surviving spouse described the aggressive approach to treatment:

Husband - They didn't know what they could do for her. The decision was mainly our's and her's that we try the chemotherapy. Then it ended up that the 5FU wasn't working and the doctor recommended trying this experimental drug. And at that time, what he said is that we haven't run out of things that we can try. It almost looked like there were several things that he could do, try this, try that, and maybe eventually we'd hit on something. And since she didn't have difficulty at all with the 5FU treatment, we figured, okay let's go ahead and really purge this thing.

The labelling of this situation as incurable did not occur. When the patient did die at home in the night, an ambulance was called and cardiac resuscitation was attempted for forty-five minutes. The family described these decisions and the aggressive care the patient received as excellent.

In contrast, families would attach the label "incurable" to the disease at the time of the diagnosis. This was usually a result of the information given by the physician at the time of diagnosis. In some cases, the label of the situation

as "incurable" was assigned prematurely by patient and/or family. In one case, the patient believed that cancer automatically meant death. She delayed intervention for a number of years because she thought that there was no possibility of treating her condition.

Families also described the labelling of the disease as incurable as a result of their observations of the patient's symptoms. They sometimes stated the knowledge as "they just knew", and did not need to be told specifically by anyone. For example, an elderly surviving spouse said that the doctor always told her that her husband had emphysema, but she believed "it must have turned to cancer". She stated, "for myself, I could see him going down, you know, he wasn't as good. I knew he was terminal and the doctor, I guess he knew that he was finished."

The definition of the disease as terminal by families was a very significant part of their experience. This interpretation of information affected decisions and interactions between family members. This theme identified the difference between information and understanding or knowledge of the situation.

5.7.4 Hope

The fourth property that was identified within this category was the notion of hope. Hope referred to the expectations or anticipations by the family and patient of what

would happen in the situation. In some instances, hope was described in terms of the expectations for more time with the patient, or wishes for a delay in the illness process. The wish for more time often resulted in an aggressive approach to treatment. This was true in cases where the patient was seen by families and health care providers as young.

Husband - I thought we could go alot longer, until about the last week. I had not given up hope until the last week. That was kind of it for me. I felt you know, at least we can get it to stabilize where it is, and maybe there's some hope of, if we hang on a month, then maybe we can hang on two months, three months...

In some families, the hopefulness they held onto affected their awareness of symptoms that indicated physical deterioration of the patient:

Husband - What happened was I could see a marked deterioration and on the other hand was still hopeful that this was just because of the radiation.

One family took the patient to a clinic in Texas that utilized an unconventional form of treatment - a drug made from urine that was injected into a vein in the patient's neck. The patient was eighty years old and was diagnosed as having pancreatic cancer that had infiltrated the liver, stomach and lungs. The reason for seeking alternative treatment was because the traditional medical practitioners had offered "no hope." In contrast, the hope that the unconventional treatment offered was described repeatedly:

I- So then when you went to Texas and she was getting this treatment how was it then for her?

Daughter - She lived in hope. Her appetite returned at that time, which was quite amazing and she was hopeful and we were hopeful. And we saw the last two weeks there was no hope because she started to, jus a total breakdown of everything. But up to then, he promised her nothing and he said I've been successful with one person like you and he's more successful with lung cancer but I'm told any type of therapy is more successful with lung cancer. He gave her hope though and this was important. I feel wonderful having met such a person.

Hope was important in helping patients and families cope with different stages of the patient's illness. At the beginning of the disease process families talked of their hopes for recovery, and hopes that things would not be as serious as they turned out. For example, one widower stated that at the beginning "there was hope that it wasn't going to be as bad as it was". These feelings were expressed before the patient's surgery had been performed, and before the family knew the definitive diagnosis. The patient, a forty year old woman died ten months later.

In some instances, hope of recovery or remission left survivors unprepared for the death of the patient. For example, a thirty-seven year old woman with metastasized cancer of the colon underwent a very aggressive chemotherapy and radiation program even though her prognosis had been very unfavorable. The family interpreted these efforts as hope for recovery and were shocked when she died.

Another example of the presence of hope occurred in a family where the husband kept the diagnosis from his wife for the entire course of the disease. He described his hope

for a cure as a sustaining belief that helped him cope with the loneliness of his knowledge:

Husband - Now the reason I hide because, she could collapse fast or she could go for many years. But I was hoping already I'm not too religious, but in this case maybe, eh? And then I says well if I talk then she collapse, but if I don't talk, maybe we never find something to cure. But I was hoping. The doctors say fine. I was reading all medical reports in magazines, Macleans, Time, if something is found we will find out. So if there is a cure you'll know. First time I thought we got five years, we got plenty of time to find something. There's always hope. The doctors they make big progress in every respect.

Families also said that they would often decide, with the patient, to proceed with treatment for which there was little expectation of recovery because it was the only thing that offered hope.

I- And so if you make the decision again, would you still go ahead with the chemotherapy?

Husband - Oh yes. That's the only means they've got. What can you do?

Participation in experimental trials represented an active approach to the disease and gave patients and families hope and a feeling that they were fighting back:

Husband - At her next appointment the doctor said that there isn't a drug that is effective for this particular variety of cancer. There is one drug that has been in use for about twenty years or so. It's 5FU and it isn't very successful on it at all but it doesn't really have much in the way of toxic side effects and he did say that he had two patients in some ten year span that did seem to respond to this drug. He said there was no harm in trying that anyway. The doctor was working in conjunction with another fellow who actually specialized in that variety of cancer. We felt that at least we had the best doctors available. Anything that was going on we'd know about. And they were actively doing research in this area.

For some families the notion of hope was described more desperately with a willingness to "try anything" or "grasp at any possible treatment". A surviving daughter described the family's willingness to try anything when her mother was given no hope and they "couldn't accept the fact that she had to sit down and die."

Daughter - "I want to try anything," she'd say. John (son) would say "this is the place." And she would say, "anything, yes I want to go". In fact, when she found out she had cancer right at the beginning of April, they had to move out of the house, my brother said to her, at this point we thought we should take her to Texas, but he heard of another doctor, Dr.R. He gives you a diet and he's cured everybody, arthritis, rheumatism and I don't know about cancer. Well, John wanted her to go on this diet, it was only eating vegetables, no protein. My mother was willing to try that. About a week later John came and said, "you know, you've been on this diet for a week, you're losing a lot of weight, but you were supposed to lose weight and rid your body of the cancer." This was this man's theory, which was really so crazy when you think of it. We were trying anything we could think of.

The daughter described her brother's hope for the diet and the family's need to believe in some type of treatment:

Daughter- He hoped maybe the diet, he knew the writing was on the wall, he knew once it's in the liver, the lungs and probably the pancreas. Although the ultrasound didn't indicate so. But the doctor said it probably was.

I- Did he really believe in this or was he then looking at it for the hope factor?

D- We all started, we read his book and we started to believe in it. But then afterwards, we saw it was ridiculous. I guess the diet, we believed in it, we were hoping, we were trying anything.

I- Really grasping at that point?

D- Grasping, yes.

It was evident that hope was very much apart of the meaning families gave to the terminal care experience. Hope was described in relation to how information was perceived; how treatment and the illness process were viewed and the kinds of expectations families held.

5.8 SUMMARY

In summary, the category identified as "the meaning of the situation" was the framework within which many other decisions were made. The theme involved a further step than simply obtaining or not obtaining information. This category differentiated between information and knowledge. Knowledge involved the families' interpretations and synthesis of facts, observations and prior experiences. Their definitions of health and illness affected decisions about when to seek treatment and their knowledge of the severity of the disease. There were also examples of the different ways families responded to and interpreted facts. The clarity of presentation of information was identified as significant to the potential confusion of families' interpretations.

A third issue emerged separate from the families' knowledge of the diagnosis. This was the families' label of the disease as incurable. The time at which this label was given was not the same for all participants. As a result, interactions between participants were affected.

The last concept that was present in this theme was the notion of hope. The hope held by families affected the ways that information was heard and the meaning that families gave to the terminal care experience.

Chapter VI

THE FINDINGS - PATTERNS AND CHARACTERISTICS OF FAMILY INTERACTION

6.1 INTRODUCTION

The study indicated that there were identifiable tendencies of behavior between individuals as they interacted about choices made in the terminal care situation. These were labelled patterns of family decision interaction and were evident in three ways: (a) one-person decision making patterns, (b) joint decision making patterns, and (c) mysterious or unknown decision making patterns.

Characteristics of these patterns were also noted. These were the qualities of the behavior between individuals as they made decisions. Four characteristics were defined: (a) decision making conflict, (b) interactions of indecision, (c) fortuitous decisions making, and (d) planned or organized decision making. The ways that the characteristics of interaction occurred with the different patterns of interaction varied, and one could not predict the association between the two.

6.2 PATTERNS

6.2.1 One-Person Decision Making Pattern

This pattern refers to the tendency of the decision making to rely on one person in the family. In some instances, the decision maker was the patient and the family respected his or her wishes and decisions. There were many examples also of the patient's control in decision making, especially the decision of where the patient would die. The family generally accepted the choice the patient made even though they often had anxieties about managing the patient's death at home.

I- So she died at home.

Husband- Ya, she wanted it that way. That's what she wanted.

I- And that's what you wanted too?

Husband - Well, it's what she wanted. It's not what I wanted, but it's what she wanted.

In some families the one-person decision maker was a strong family member, sometimes a son or daughter. In these families the decision maker was actively involved in obtaining information, acting as the switchboard operator between family and physician and was usually not the direct caregiver. Families relied on this person heavily and supported this decision making pattern with little conflict. This pattern was not discussed as the form that decision making would take. Rather, the stronger decision making person would assume the role and the others became less active. A

distinguishing characteristic of this pattern when it was assumed by someone other than the patient, was that the decision maker protected the others, experienced the weight of responsibility, and often controlled the information available to others. For example, one spouse assumed a very strong decision making role in the care and had frequent direct contact with the physician. Together they decided that the patient should go into hospital and stay in hospital. The patient was not included in this decision and the spouse described his intentions in keeping this decision from her:

I- What was your thinking at that point?

Husband - Just trying to keep everything as calm, like in terms of not telling her?

I- Yes.

H- Just really to keep everything as calm and quiet as could be. And I didn't want to have Joan be worried about anything extra at that time. So I just didn't feel it was necessary at that time to tell her that she was going in and staying in until it gets better.

The interactive element of this pattern was quite evident. In families where patients were more passive, a family member usually took a stronger decision making role. In families where the patient was more dominant, families stood back and complied with the patient's decisions. The way this pattern developed was not discernable. It was not clear whether the patient became passive in response to a more dominant family member's control, or whether that person became more controlling in response to the patient's depen-

dence on them. Although the sequence of this pattern was not evident, the interactive quality of the pattern was apparent.

6.2.2 Joint Decision Making Pattern

Joint decision making patterns referred to patterns of decision making that occurred in a collaborative form within the family. This was a commonly described form of decision making.

Husband - And we had both decided when the whole situation started that as much as possible for as long as possible we would try and keep everything as normal as possible. And especially when it came to the kids. That would be our number one priority regardless of what was happening to either one of us, was that we would try and make sure that their lives were as normal as possible. So that was something I felt we'd made jointly.

Many families described the ways they discussed information and alternatives as they arrived at joint decisions about treatments, daily care, and death related plans.

I- So the doctors and yourself and your wife were all participants in the decisions and she had alot of final say.

Husband - That's right. Or she and I would discuss it between us, or my daughter would discuss it and we'd decide what to do.

Families also talked of the kind of joint decision making that occurred as a result of years of knowing each other. These decisions were not as frequently discussed, and were stated more in terms of understood preferences. In these families, decisions were assumed rather than negotiated and

there was a calm assurance that individuals knew what each other wanted. This was particularly true of elderly couples who experienced the terminal illness of one partner. The years of knowing each other allowed these families to proceed with many decisions without negotiation or discussion. One widow remembers the way it was decided that her husband would die at home: "It was never really discussed, it was just assumed that he would be here, and I never wanted to change that."

The awareness of the patient's preferences in decisions was apparent when the patient deteriorated physically and decisions had to be made on his behalf. Even though they were not discussed, the decisions represented a mutual understanding. For example, when decisions were made as to who would be present when the patient died, families represented the patient's wishes about this decision. One widow talked of her knowledge of the patient's preferences about who should be present on the day that he died: "Well, I know he wouldn't have wanted the family to come really, and yet he didn't want to say don't, I know he wasn't, well, he had a great need for a sort of orderly day."

In some families, decision had been made jointly years ago in preparation for the death of one or the other spouse. In these situations, families were able to make decisions quite easily because they knew what the patient's preferences were.

I- Had your husband made any arrangements or talked about how he wanted things to be after?

Wife- Yes, well we both had done that a long time ago. We paid for our plots and funeral and everything. When you're our age you think about things like that. And we didn't know who would go first, and to leave the other one with all that to do wouldn't be very good.

I- It sounds like you had planned things.

W- Yes. We were prepared and we wanted those things arranged.

Another older couple had discussed decisions about cremation after death. This represented a planned joint decision.

I- Had your wife made any of those plans herself? Had you talked through those decisions?

Husband - We hadn't made any plans but we said we wanted to be cremated. Immediate cremation, so that's what happened.

I- That was a decision you two had made a long time ago?

H- Ya, we said that a long time ago. We both said we wanted to be cremated.

It appeared then, that joint decision making could be either negotiated or understood. Families collaborated and discussed alternatives and made numerous decisions using this pattern of interaction. The interaction between family members in these situations was described as supportive.

6.2.3 Mysterious/Unknown Decision Making Patterns

The pattern identified in this category referred to choices that occurred and affected the family when the family had no knowledge of the source of the decision. This pat-

tern was evident when families described events as simply "happening" and when questioned about who made those decision they did not know. They generally supposed decisions originated with physicians when they were unsure of the source. This pattern of decision making interaction was most frequently seen when families were asked about home care arrangements.

Wife - The orderly came just a month before he died, but the nurses had been coming here for over a year.

I- Did Dr.X. arrange for the nurses to come?

Wife - I don't know. I guess so.

I- Who decided that it would be good to have an orderly?

Wife - Well I guess it's Dr.X.

Often, the home visiting nurse would be described as being involved but families did not always recall how they accessed this resource or who "sent the nurse". Their vagueness about how home care needs were assessed and how they obtained home care help sometimes resulted in inadequate services.

I- Did she have Home Care at that point?

Husband - No.

Sister - Not at this point.

Husband - We eventually did get home care, but not right at that time. The last ten days or so we got home care.

Sister - She certainly needed it then of course. It would have helped to have it sooner.

I- Who made the decision to have Home Care?

Husband - Well we had a visit from the V.O.N. and I guess she assessed the situation and decided that we needed ti.

I- Had VON been coming in from time to time?

Husband - They were supposed to have been. They weren't coming very frequently at all.

One family described their distress and confusion when they found out that the patient was going to be sent home from the hospital and was to be "taken off all treatment". The lack of communication between family and physician left the individuals wondering about the source of this decision and the rationale behind it. The daughter stated: " I don't know. It struck me at the time. What is going on? Have they given up, or was it mother's decision or what?"

The mysterious or unknown decision making pattern was less common than the other two patterns of interaction. However, the effect of this pattern was described as significant to the terminal care experience.

There were occasional blends of decision making patterns within the same family. Sometimes decisions were made solely by the spouse. For example, one widow recalled the decision about where the patient would die: "We always let him decide what he wanted to do. The only thing I didn't agree with him about is when he wanted to die at home. I didn't like that."

The same spouse might be less active in the other decisions and a different decision making pattern might be seen in the same family. However, the decision making pattern within the family was generally quite constant.

6.3 CHARACTERISTICS

6.3.1 Decision Making Conflict

Conflict in the decision making process referred to disagreement in the family about the terminal care choices. This conflict was evident in all three patterns of decision making interaction. In some cases, the decision making control of the one-person decision making pattern resulted in conflict and strain among families. For example, in one family, the surviving spouse had decided who would be present at the time of the patient's death. This resulted in continued strain for the family.

Wife - I think that my daughter felt badly that she wasn't here when X died, she had asked if she could come and we knew that other members of the family were going to be here and I didn't know how I was going to deal with that, and she felt really badly that she wasn't here. And Bill's wife was here, she was very fond of X but she was afraid to help; but Ellen felt she should have been here.

Families often experienced strain when the definition of the situation as terminal was unclear and communication between family members was poor. This sometimes resulted in decisions about visiting the patient that were conflict producing for families:

Wife- You know I really felt bad. He said, "Tell Louise to come and see me" (his sister). So I said, "Okay, I'll phone." So I phoned to her. She was too busy, too busy. Her husband, that's my brother, he said, "go, you've got only one brother, that's all you've got in the world." He said, "Go, take the bus and go." But she was too busy. After he died she said, "I'm sorry I didn't go and see him." Well it's too late. I told her, it's too late now...

One family experienced disagreement over where the patient would die. The patient wanted to die at home and the spouse did not want that to occur:

Wife - He didn't want to go to the hospital, he wanted to die at home. I said it's too hard on me if you die at home, it would be so much different, if you, you know...

I- But he really wanted to.

W- Ya. But you never know what kind of a fight they'll put up when they die. This is what I was scared of. He was still a strong man.

I- It's alot to deal with by yourself. So when you told him you really didn't want that, did he agree?

W- Oh yes. What I said went.

Conflict also occurred when decisions depended upon the length of time families expected the illness to continue. This factor affected their willingness to care for the patient and commit themselves to participate in the care.

Daughter - The big decision was, my brother thought my father should be in hospital when he saw the magnificent care my dad was getting. And he said, "there's no way this could happen at home." But my Dad well at that point my Dad was so dopey, but he kept on saying to Dr.X. "when am I going home?" And my sister wanted very badly he should go home and be in his surroundings and die at home. My brother felt for everyone's sake, he thought that I would have to be very much involved because my sister Sandra, which is true, because up until then she didn't know if she even wanted to remain in Winnipeg that whole time. So it was, the whole load was on my shoulders.

Families also experienced conflict over decisions to be involved when responsibilities in other relationships were affected. An example of this type of conflict was the mari-

tal strain that occurred because of the involvement of one partner in the care of the patient.

Daughter- Although the apartment is a few blocks away I had children here to take care of, although they aren't babies. Just to make sure that their needs were met. And my husband was not too supportive. He, I guess, well I guess when it's not your own parents, and he also comes from a family where there is absolutely no involvement, his mother died when he was thirteen. He just didn't understand. To him it was almost craziness. So I was actually alone.

The conflict related to decision making took many forms and occurred in all patterns of interaction. The effects of the conflict also continued after the death of the patient. Some families were not on good speaking terms with each other, one couple was seeking marital counselling and others simply continued to feel "strain" in relationships. The extent to which these conflicts were present before the terminal illness episode was not described. It appeared though, that the decision making process brought forward many examples of conflict within families.

6.3.2 Interactions of Indecision

This characteristic of decision making referred to discussions and considerations in a family related to matters that delayed a decision or resulted in no final choice. This situation often occurred when there was a joint decision making pattern in the family. Periods of indecision also were evident when families felt limited in information and understanding about the situation. This occurred again, when

families did not know the time frame of the disease process and were unsure of the severity of the terminal illness. An example of this type of indecision was when there was discussion about the patient coming home to die. For example, one surviving daughter recalled her feelings when she was told her mother was coming home to die:

Daughter- Have they given up or was it X's decision or what? I didn't like it, but then again, we didn't know the time frame. Six months? A year? Ten years? We didn't know. That was the thing that bothered both Dad and I. They could have given us...well, maybe they don't know, I don't know.

I- So you were feeling kind of uncomfortable just about all the unknowns, if you'd known what you had to deal with you would have..

Husband - Probably handled it.

I- So if you knew she was coming home to die within a month or so or six months, you could have prepared yourself.

Daughter - Yes, I could have taken that time off work. Stuff like that which we hadn't prepared to do.

Families also experienced indecision when they felt caught between the known preferences of the patient and their contrasting view of his needs. For example, one patient had particularly stated that he wanted to die at home. The family accepted this decision. However, later when his condition became worse and he lost consciousness, his breathing was very labored and the daughters believed he needed oxygen. They did not know how to obtain oxygen quickly in the middle of the night without calling an ambulance. The wish to respect the patient's choice of where he wanted

to die conflicted with their assessment of his comfort needs. The interaction between family was one of anxiety and indecision. There was then a delay in finally calling the ambulance. In retrospect, the family did not like the way the decision went, but did not know what else to do.

Interactions of indecision were not as frequent a characteristic of family decision making as some of the others. However, the effect of this type of decision was often stressful for families and unfavorable for the patient. Episodes of indecision were often described when the family was missing information with which to base a decision or when they did not know how to operationalize the different options.

6.3.3 Fortuitous Decision Making

This type of decision making occurred when choices were made within the family that were described as lucky or happening by chance. One example of this type of decision interaction was when the patient was taken home from the hospital and died at home. This was preferable to the family and patient, but they had not been prepared for the patient's death when it occurred. Therefore, this choice had not been made consciously.

Sister - Yes. It was lucky too that we'd brought her home. She was getting depressed so we asked if she could go home, nobody suggested that she go home. That was just two weeks before she died. I felt we were lucky to have her home. She was going to go home for a weekend and we decided because she couldn't have the treatment, she may as well

stay at home and you can test the urine from home. That was just a godsend. It just happened that way. No one ever said, "if you want her at home you better take her now or whatever," there was none of that.

Families also described actions taken and decisions to be with the patient when they "felt" that something was wrong. These decisions were not logical planned choices, but were stated as an impulse or an intuitive sense that they should be with the patient.

Daughter - And my Father and I went downstairs to eat and we went and got a coffee and sat down and said something's wrong and went right back up. And she was in asphixiation.

Husband - She couldn't breathe. She had an obstruction in the throat.

The family could not explain why they had felt the urge to return to the patient, but were thankful that they had responded to their intuition. This was seen as a fortuitous decision. These decisions were less common, but certainly represented an important part of the terminal care experience for families and were remembered as "decision making events".

6.3.4 Planned/Organized Decision Making

The choices made within a family that resulted from arrangements and preparation were classified as planned or organized decision making. This type of decision making occurred most frequently in a one-person decision making pattern of family interaction. In these situations, one per-

son would plan and direct decisions and arrangements. For example, one spouse who became the decision maker made the decisions related to the terminal stage of the patient's condition and the death related decisions. His knowledge of the patient's impending death allowed organized decisions.

Husband- It was her last day. And I knew because I was following her so close. As a matter of fact, around six o'clock, now you were asking me if a priest was involved. The priest used to come. But that night I told the kids I'm going to go get the priest. They looked at me as if I didn't know what was happening. So I went to get the priest. He came at seven and left at eight. At half-past nine she was gone.

The time element also was relevant to the families' ability to make planned and organized decisions. In instances where decisions had to be made quickly, families were more stressed and relied more on physicians for those decisions. In decision making processes where families had time to prepare and plan their choices, more organization took place.

The organization around the decision making process was described more positively by families than the chaotic type of pressured decision making that families experienced when they had little time to consider alternatives. It was noticeable that when a family had the same decision to make a second time, the organization and clarity of that decision was much more evident. For example, one family experienced the death of both their parents due to cancer within six months of each other. In the first instance, the family decided in favour of heroic resuscitation procedures. They re-

gretted this decision and saw it as inappropriate afterwards. The daughter stated:

Daughter - And it was terrible because my mother was unconscious when she went there and then she became conscious suddenly and was yelling, "I'm dying, get me out of here". And they treated her like, we couldn't believe it, what went on. And we wanted to avoid this with my father.

Later the daughter said her sister made the decision to not have the health care providers use heroic resuscitation procedures with her father when he died: "My sister said they had asked if they should take any measures, heroic measures. And she said, no, and they said that that was a good decision."

The importance of having information related to the decision was then part of an organized decision making experience for the family. Families also needed to be able to interpret the information accurately and had to have some time to make the decision as well, if planned decisions were to occur.

6.4 SUMMARY

In summary, three patterns of behavior were identified between individuals as they made terminal care decisions. These patterns were either decisions controlled by one person, or were joint decisions by a number of family members. The third pattern of decision making involved situations in which the decision maker was unknown. These patterns could result in conflict within the family or in delays in final

decisions. The interactions in relation to decisions varied in terms of organization and planning. The quality of the interactions about decisions and the decision outcomes were related to the relevant information available to individuals, the meaning that different family members made out of the facts and their observations and the communication between participants. There was a type of decision making that was experienced by families as fortuitous or fated decisions. While these were more infrequent types of decisions, they were cited as important by families.

Chapter VII

THE FINDINGS - PLANNING FOR DEATH

7.1 INTRODUCTION

Families identified the death experience and the related decisions as a very important part of the terminal care process. The extent of organization and preparation that families had prior to the death of the patient was part of the experience families described. The actual death of the patient could be peaceful or disruptive. The timing of the patient's death was also described as affecting the families' preparation for death. The death could occur anywhere along the illness trajectory. The extent to which this timing was expected marked the experience for families. The death scene itself was a vivid part of the families' memories and included the decisions and participants involved. One particularly significant decision in this stage of the experience was defined as the "where to die" decision. The awareness of the patient's impending death influenced the extent of preparation that families had. Also, there were a group of decisions described as death-related decisions that had to be made at the time of death of the patient. These aspects together created the way in which families planned for the death of the patient as well as the death experience they remembered.

7.2 PEACEFUL VERSUS DISRUPTIVE DEATH

An important part of the experience described by families was the way in which the patient died. This included the family's perceptions of the patient's suffering at the end, the speed of death and the maintenance of the patient's dignity in the last stages of dying and death. These memories could be summarized as representing either a peaceful death for the patient or a disruptive death.

Some patients experienced a calm death whereby they gradually lost consciousness and "slipped away". These experiences were the least stressful for families and families saw these deaths as a gentle release from suffering. The ease of this type of death was expressed with phrases such as "she just went peacefully in her sleep", or "he just looked like he was sleeping". For these families, the patient's death was not seen as painful or uncomfortable, they expected the patient's death when it occurred, and the death did not decrease the patient's dignity.

In other instances the experience was very different. Families described in great detail the ways in which the patient died. Many remained emotionally upset about the loss of dignity and suffering that the patient experienced. These memories were held by the family with pain and often guilt that they could not have prevented such a difficult death. One family recalls the patient's death with much regret. They had made a decision to have the doctors attempt resuscitation procedures on the patient.

Daughter- The big shocks that you have to get away from the bed. And she had oxygen on. It was awful, awful to see that. And they wouldn't let us go into the room. I don't know what they were doing and we should have been there. She wasn't unconscious at that time and when we finally went into the room she was screaming for us and she saw us and she started to scream "get me out of here, I'm dying and I don't want to be here" - and very lucid.

The guilt experienced by the family related to this decision was described:

I- You made the decision to go ahead with aggressive treatment, to resuscitate, how did you feel afterward?

Daughter- Well, my brother felt terrible. I was just in a state of shock, I couldn't believe she was dead, 'cause to me she looked like, you know, she was sleeping. And he said that from what he's read, people when they reach the last stages are quite peaceful. And then just to look at those shocks they administered to her were just terrible. He still can't forget that.

The family was not prepared for the patient's death. They described it as a "shock" and said later that they did not understand what was happening when they made the decision to proceed with resuscitation procedures. When the patient's condition worsened the family called the physician and recalled the following exchange:

Daughter - He said "you have your choice, do you want your mother to go to the hospital or stay at home?" Well I thought, what kind of a question is he asking me? Of course, the hospital. But he was telling me that your mother's dying.

I- He was saying do you want to go to the hospital to die and you thought to go for care?

Daughter - That's right. And he said, "if she should die do you want us to take what do you call these, radical treatments, with shocks and everything?" I said, "of course!" I got off the phone

and my brother David was there at the time. I said, "he's asking me some stupid question if we want to stay at home with Ma."

I- You didn't know what you were deciding at that time?

D- No, no, no! They asked me this on the phone, do you want these aggressive measures, I said "of course!" Like I said to my brother "what is he asking, she should stay home or go to the hospital?"

The lack of understanding about the decision made was affected by the fact that the family had not defined the patient as dying. Their beliefs about the length of time that a person should survive with cancer influenced their awareness of their mother's impending death. The family believed that patients did not die quickly from cancer. They expected a long illness with remissions and exacerbations. For them, death came too soon along the illness trajectory.

In another situation the way in which the person died was described as very hard for the family, as they felt the patient's dignity was lost. The family had called an ambulance and they remember the chaos and conflict at the time of the patient's death.

Daughter - We were crying. And they lifted him from the bed and he died instantly. They threw him in the wheelchair. They forced him in the chair, and we started to shriek and they said "shut-up and get out of my way." And of course, you just saw him, first of all, he didn't look, the last breath came out of him and then, with the wheelchair they took the oxygen and threw it on his leg. We couldn't believe it. So they took him down the elevator in the wheelchair. He was dead! He was dead! And then they put him on the stretcher and they just threw the box on his leg, you know the oxygen box I guess it is. And they were screaming at us.

Some of the chaos resulted from things that the family had no control over. For example, the ambulance stretcher did not fit into the elevator, therefore, the ambulance attendants used a wheelchair to carry out the dead patient. The family also experienced guilt because the patient had wanted to die at home. The family wanted to obtain oxygen to ease the patient's breathing but did not know how to obtain oxygen, so they called an ambulance. That decision resulted in an irreversible trip to the hospital. The interpersonal conflict in this situation was perhaps the most controllable element. The surviving daughter stated:

I said, "could you come and bring some oxygen, there's somebody dying here. Could you bring some oxygen to ease his dying." They said to me "lady, you're crazy, if we come we take him to the hospital. How do you know he's dying?" So I explained he had terminal cancer and this is just the last stages of it. "No," they said, "we can't just give him oxygen. We've got to take it him to the hospital." So these fellows came knocking and they wanted to put my Dad in a wheelchair to take him. Here he was just choking and gasping and we started to scream hysterically, "how can you put him in a wheelchair, he's dying." And they started to scream, "we can't fit this in the elevator."

The description of the interaction indicated that all participants were emotionally upset and caught in a situation that they did not like, but did not know what else to do. This incident would certainly be described as a disruptive death.

There were also examples of more peaceful deaths when the patient's consciousness was gradually decreasing and the patient's communication with the family was affected. In these

circumstances, the patient experienced a social death first and later a physiological death. One example of this was a seventy year old woman who went into a coma a month before she died.

Husband - It was peaceful. It happened in the middle of the night. She'd been the same for two weeks, almost two weeks the same. She didn't know or hear or anything else. She didn't know us at all. So you couldn't expect anything. You couldn't know that it was going to happen.

Families described this gradual loss of communication with the patient as a way for them to prepare themselves for the patient's death. A surviving husband described his feelings about his wife's death:

At that point I wasn't sure I was ready to say there was no hope. The last Monday before she passed away I came at lunch time to see her and she was essentially non-responsive to me and her right eye had kind of popped out of her head a bit. Her left eye had been like that before on occasions. When I saw the right eye go like that I knew that was the last of any hope as far as I was concerned. There was just extra pressure on the other side of the brain. Up until that time I think it had only been on one side of the brain. So that kind of gave me an indication that there were severe problems.

She didn't respond to me at all Monday until late at night when she finally said that I was there. And on Tuesday we had a pretty good visit and Wednesday she was non-responsive, that was the last day her Mom came into visit. Friends of her's were coming in from Brandon so she came in that day. I felt really bad about that because all day she just lay there asleep. But at least she was sleeping peacefully. So, that was a bit of a blessing, she wasn't in any agony. And she looked alot better than she did on Monday. On Monday she had not looked at all. We had a reasonably good visit Thursday, but Friday she was non-responsive again. And on Saturday she was non-responsive, other than I think she recognized that I was there Saturday.

The way the patient died was something that the family had no control over. If the death was disruptive the family found it difficult.

Husband - She was only home for two days. We had her home lyin on the couch and I was laying beside her, and I was up all night with her and then in the morning she started vomiting, she usually wiped herself you know, and this time she didn't and I picked her up and there were great gobs of black stuff, just looked like it didn't go out of the bottom it went out of the top. It looked like she didn't pass it at the bottom at all, you know, it was accumulating and her stomach was like a balloon.

I- That was at the end?

Husband - That was at the very end. It was terrible, especially when I had her in my arms and she did that.

Disruptive deaths were most often described by families who experienced the death of the patient at home. Although there were certainly examples of home deaths that were seen as peaceful "good deaths". The patients who died in hospital often died without their families present. Therefore, these families heard of the patient's death through the health care providers. These deaths were either assumed to be peaceful, or were stated by the health care provider in gentle terms such as "passed away" or "slept away in his or her sleep". It seemed then, that when patients died at home, the family would have a more complete knowledge of the way in which the death occurred. If the patient died a disruptive death in hospital, the family might have been protected from this knowledge.

7.3 TIMING

The timing of the patient's death referred to the point when death occurred along the dying trajectory. This was described in terms of the family's perception of the appropriate time of death and took into account their view of the dying trajectory. One surviving spouse described the fact that the patient had the disease for four years as a way of giving them time to prepare themselves for her death.

Husband - In terms of our own relationship, her's and mine, that time was very valuable to both of us despite the suffering. I think we grew alot closer to each other over the time, which we would have missed out on otherwise. And I know it certainly gave me time to deal with things that I'm not sure that I could handle if the event had been sudden.

Families also experienced the patient's death as appropriate when they had knowledge of the pending death and when the patient had expressed a readiness to die.

I- Did you have preparation that the end was coming, did you know?

Husband- Oh yes, she was ready for that, she was hoping for it, she was ready to go.

In other families the speed with which the disease progressed was described as "too fast" and families felt that the patient's death occurred too soon along the terminal illness trajectory. One daughter recalled her mother's death: "My mother I feel was cheated. It was so quick. But that's a very viscious cancer, it's a killer."

In another family the time was also seen as very brief from the point of diagnosis until the patient's death. One

surviving spouse described the speed with which the illness progressed: "It all went so rapidly though. I mean from the time the cancer was noticed as a tumor to the time she passed away was only ten months." In both situations where the timing of the patient's death was seen as too soon, resuscitation procedures were attempted on the patients when they died.

The timing of the patient's death could be either too soon or appropriately timed, according to the families. There were no families who felt that the death occurred too long after their sense of the appropriate time. The element of time was described a number of ways as significant to the terminal care experience.

7.4 DEATH SCENE

Descriptions of the "death scene" included the individuals, the setting, the time, the attitude or mood, the preparation and the actions taken by the family at the time of death. These "scenes" were vividly described by families and remained powerful parts of their memories of the experience.

In families that experienced the death of the patient at home, one concern that was mentioned was the lack of a "social script" when the patient died. Patients and families may have wanted the death to occur at home, but once it occurred there was often confusion and uncertainty as to what to do next. As one surviving family stated:

Daughter - A dead person in the dining room, my sister-in-law was hysterical no one knew what to do. Well what do you do when there's somebody in the dining room that's no longer living?! I mean there's certain things we wonder if there's social responsibilities or something you know.

The mood of the scene could be upsetting and chaotic or it could be calm and dignified. This atmosphere was described in relation to the preparation families had and their expectation of the time of death. One family that experienced confusion and distress at the time of the patient's death also said: "We were all standing around - tears, tears pouring down our faces, we didn't know what to do."

In families that were well-prepared for the patient's death, the atmosphere at the death scene was very different. One widower recalled his wife's preparation for death: "She knew right away when it was cancer that she'd pass away, they wouldn't cure her. She didn't know what time, but she expected to go. She was prepared to go." In this family, the death scene included the family members who had been called in time to come and be with the patient. The death was peaceful and the family expected it.

The interaction between patient and family at the end was also a remembered part of the death scene. One surviving spouse described the way he and his wife had a clearing of their relationship before she died. He stated: "About two weeks before she died, she asked me if we had anything to straighten out, like in our lives together. And I said, 'not

the way I looked at it', and for her there was nothing either. We had a happy life."

A surviving daughter remembered her mother's last words before she died: "Her eyes were back and I patted and shook her and I kept calling her name and she said 'It doesn't hurt Ann.' Then she went right back into that state with her eyes back and then the doctors came in and told us we should leave." This interaction was recalled by the daughter with a calm feeling because she believed then that the patient's death had been peaceful.

Families also recalled the death scene when they didn't quite know what was happening but felt the turmoil of others around them.

I- So you were with her when she passed away?

Daughter - No they told us to leave. The doctor went in. I could see. I was standing at the door and all these nurses were running in and out and I panicked really bad because I knew something had to be wrong. And then the doctor came out and told us that she'd passed away. It was just....I couldn't believe it.

There were death scenes in which the surviving family members were not present. In most instances, families experienced guilt and regret at not being present at the patient's death. The decision about whether or not the family would be with the patient often occurred without realizing that the patient was going to die. Sometimes a nurse would say to the family, "why don't you go home and get some rest." Later, if the patient died, the families regretted

having left. The loss of control over who would be with the patient when he or she died occurred most often when the patient died in hospital. A surviving spouse stated:

Then the next morning I phoned at about quarter to eight and they said, "just a minute, the nurse is with him." So then I waited and a doctor came on the phone and said he just died. "Well," I said, "Why didn't you call me? No one was with him. He shouldn't have to die alone like a dog!" I really regret that I wasn't there.

The presence of the family at the time of death was important to families when the patient was believed to be conscious near the time of death. If the patient was not conscious, this was less of a concern. For example, one surviving spouse did not feel badly that he had not been present when his wife died because she was in a coma and he believed that his presence or absence was unknown to her. He stated:

She didn't know us at all. So you couldn't expect anything. You couldn't know that it was going to happen. We could have sat there twenty-four hours a day, but you wouldn't know what was going to happen.

Sometimes, families had fears of what the patient's death might be like. These fears sometimes influenced their decision of where the patient would die. For example, one elderly lady refused to have her husband die at home because "you never know what kind of a fight they'll put up when they die" she believed. Another patient had fears that she would suffocate at the end. It was a relief to the family that her "breathing was fairly good and she never gasped for air."

It seemed then that the preparation for death and the timing of the patient's death made a difference to the atmosphere and decisions made at the time of death. While families said they were often told by nurses or doctors that the end was near, or were asked if they knew that death was coming, the realization of what would happen was not clear until the death actually occurred. These families thought they should have been better prepared with more specific information.

7.5 THE "WHERE TO DIE" DECISION

The "where to die" decision referred to the processes and outcomes of the choice made by those involved as to where the person should die. Some families did not discuss this decision, but rather said they knew or understood the patient's preference and that there was an "understanding" as to where the patient would die.

Husband - Now with respect to the question about whether or not we had discussed where she would be at the end; the nurse raised that question with me that very week, I guess on Tuesday. She said "have you discussed this or thought about it?" And at least I was thinking about it at that time. Although we had not discussed it because it was I guess a difficult thing to discuss at that time because well first of all, she wasn't lucid most of the time and I think in my mind I had decided that it was better that she be at home. I think that's what she wanted.

In cases where the decision was made to die at home, the patient was usually the main decision maker. For example, when one woman heard her prognosis she stated, "I'm going

back home and I want to die at home, I'm not going to die at this hospital."

In families where the patient died in hospital, the decision was not really discussed. There was no question raised as to whether or not to go home. These patients were often receiving more aggressive therapeutic intervention. Physicians were therefore, more dominant in medically-related decisions and families and patients were more passive about taking initiative in directing the care decisions.

The outcomes of the "where to die" decision were varied. Some families felt positively that their family member had died at home. For example, one daughter said, "my father died the way he wanted to. He died at home."

Another family had experienced confusion and stress when the patient died at home because they did not know what actions to take once he died. However, their view of the experience was still very positive:

Daughter- I feel that if people have the chance to lose someone that they really love in such a nice way. People that have to trek to the hospital every day to see the person getting worse and worse, I think that if you have the chance to keep somebody at home, if that's at all possible, that is the way to go.

Sometimes the patient's decision to die at home was not the family's preference. The family would agree though for the patient's sake, even though they experienced anxiety about the decision.

It appeared that the "where to die" decision was only one decision that resulted in a number of outcomes for the family. The preparation for the decisions and role of the family in cases where the patient died at home were seldom discussed. The preparation was often vague and the only main decision that had been made was that the person would die at home. Beyond that, families did not know what to do or what to expect. Therefore, the home deaths provided families with the structural control over the death experience, but gave them little preparation over how to manage the outcome of that decision.

7.6 AWARENESS OF IMPENDING DEATH

An important part of planning for death was the family's interpretation of the signs and symptoms of the patient that indicated approaching death. Families that knew the signs of impending death had more time to prepare for the event.

Husband - It was about a week and a half before she died, all of a sudden, one morning she said I'm not suffering anymore. And one girl, Suzanne says it's a miracle. I know what miracles are, so I didn't say anything. I went down the basement and I grabbed the phone and I phoned the doctor and I said by-the-way I said what's the explanation for somebody who stops suffering? Well, the doctor says the nerve tips are damaged so much that there's no more connection. That's all I want to know I said, and I hung up. But when the kids saw that their mother had stopped suffering, they thought she was cured. I tried to explain to them, I said, "look your mother's not cured. She just stopped suffering." As a matter of fact, I said, "when that happens it's a matter of maybe a week, the most two weeks."

This family was able to mobilize resources such as a priest and a friend who was a nurse to be present at the death scene. The patient's family was also called in time to be at the death-bed. This was important to the family. In this way, they experienced a death with the patient with some preparation and control.

In contrast, other families reported not knowing at all the signs that indicated death was imminent.

Sister- Before she died on Friday night she had no pain. We had no idea what that meant and I really wish we had. Now that I had an idea what that represented. We asked her if she was having pain and she said no. And we cut it down leaps and bounds. In fact we stopped medication and bolted it down which you shouldn't do and still it made no difference. She was pain-free, but at least asleep. I was a little bit upset with Dr.X. at the end too. Of course, he wasn't here to see her. But when the pain dropped like that, like she had none, we were just dropping drugs right, left and center, he wouldn't have said, make a house call or bring her in or said something.....

I- to help interpret what that meant..

Sister - That's right, it would help to interpret what that meant.

The fact that families were unaware of approaching death meant that they did not make arrangements and decisions that they could have had they known.

I- The only part you say you may have wanted more preparation or more information was the end?

Husband - Yes. Because it was something that was too unexpected, in a way.

I- You might have had some decisions to make if you'd known you had decisions to make, where to be, who to be here and what kind of action to take.

Husband - Yes.

Sister- Yes, and Donna (daughter) was away for the weekend.

Husband- Yes, her father was away at the lake, her brother was away at another lake, Donna was away at another location. In fact, we didn't expect it right at that time.

Families also had their own ways of knowing that death was imminent. These families said they did not need to be told the patient was dying, they could tell by their own observations. For example, one man described his wife's last week:

Husband- That was on the Sunday and on the Saturday she passed away. She got worse. I could always see, how she always came to the table for meals you know, and then, Friday morning she came for breakfast and I cooked her some cream of wheat, she ate a little bit too, well she ate the usual. Then, she was going back to her bed she said she wouldn't come to the table anymore, it was real hard, I had to help her. And Saturday morning she didn't come. Friday noon or supper. Friday morning. That was the last time she came to the table. But she ate Friday and she ate Saturday morning, a little breakfast. And she even ate a little bit of watermelon on Saturday. At Saturday noon, around one o'clock she didn't talk anymore. She talked until one o'clock and at three o'clock she died.

Sometimes the awareness of the patient's approaching death was unspoken and remembered as "intuitive" by the family.

Wife - I could see he was worse though, they'd taken out the tubes intravenous and everything and I knew he wasn't good. So I said to him on the Saturday night, I'll see you in the morning. I don't know why I said that. I always went in the afternoon at visiting hours. But he just smiled, like he thought, you may see me, but I won't see you.

One surviving spouse described his memory of the patient's last hours and his feeling that the end was near.

Husband - She seemed to be having more difficulty, and I just had a feeling that there wasn't much time left. And I said to myself, I think I'll go home now and come back early in the morning because I think she'll have trouble in the morning. And so I left at quarter after eleven, and I stopped at the nursing desk, I said, watch Jean close tonight because she's having more trouble than usual.

The accounts of these types of knowledge about the patient's nearing death are stated in retrospect. One wonders what meaning was attached to those perceptions after, as opposed to before the patient's death. It was interesting that often the same families stated that they were surprised when the death did occur. These families may have known at some level of awareness that death was approaching. However, this awareness may not have been as clear prospectively as it was later. In retrospect, with the confirmation of the patient's death, those "hunches" or "feelings" may have then become more significant. Regardless of this phenomenon, most families expressed a wish that they had had a clearer knowledge of the patient's impending death before it occurred.

7.7 DEATH-RELATED DECISIONS

There were a number of decisions that were necessary around or after the death of the person. This theme included those decisions and the processes involved in arriving at those choices. One decision that was often made, was who was to be present at the time of death. This decision was dependent upon the family's preparation for death. In sudden death events, this decision was not made. This decision did result in guilt, regret and at times family strain when family members were not notified in time or were not invited to be present.

Son- When you have to tell your relatives it's hard. Like I met my uncle and he said, "how's your mom?" and he hadn't been told. What do you do? You are right in the shopping center, you can't really - I told him and he said "how come you didn't phone me?" Well there was a mix up because we thought they knew. So they burst out crying in the middle of the store and that really made a scene.

Other decisions that had to be made related to the death of the patient were the matters such as what to do with the deceased person when they died at home. This was an issue of much confusion and discomfort for families. One example of the lack of preparation in the death system for this type of death occurred in the following way:

I- Did you have a doctor come then?

Husband- He wouldn't come. We phoned the undertaker. He said, "I can't remove her until I have the doctor's signature." So I called Dr.X. and he said, "you don't need my signature." I said, "you're not coming down?" He said, "I don't have to." So he didn't come.

I - And then what happened?

Husband - The took her down to the undertaker place. It was awkward. Especially when I had Dr.X. on the phone and it was a Monday night and he could have come down for sure. He said, "I don't have to, I know the law. I don't have to be there."

I- Did it take a long time for the undertaker to get here?

Husband - Oh it didn't take them long. But the thing is they put up an argument with us. They said, "we can't do that, we know the law, we remove on the signature of a doctor."

I- But then they finally did?

Husband - But they finally did, they did after that, but I mean it's a... (shakes his head, upset)

Families reported not knowing who to call when the patient died, they did not know the social procedures in this situation and often impulsively made decisions to call ambulances or the police when the patient died at home, even though the home death had been decided upon.

I- What about at the end, she was at home when she died?

Husband - Ya, well, I knew she was dead.

Son- I went and phoned everybody.

I- Did you call an ambulance, or a doctor?

Husband - I didn't do anything.

Daughter - I called my aunt and she called the ambulance.

Husband - The minister came right away. The ambulance was no good anyway - they can't do nothing those people. He came in with all the stuff for life saving. I told him it was no use.

I- So did they come in and take her?

Husband - No. There were two ambulances here and the police were here. And the police phoned the pick-up you know. I knew she was dead. I closed her eyes and cleaned her up. And then I layed her down and then the ambulance checked and the police came and phoned the van to pick her up.

Son- Everybody was in quite a panic here.

Other death related decisions included whether or not to do an autopsy. This was a difficult decision for families and sometimes there was disagreement related to this decision.

Wife- After he died they wanted an autopsy and I said, "No, he's been here long enough, if you don't know what's wrong with him by now it's too late." But my son said, "Yes, if it can help someone else."

I- So they did the autopsy?

Wife - Yes, then I asked my doctor if they have to tell you what they found. And he said all they would say is he had lung disease and died from heart failure. So what news is that?

The other death related decisions included telling children about the death of a parent and how to do that. In most cases parents had prepared their children for the patient's death in some ways. For example, a young mother tried to prepare her children for her death.

Husband - I remember she started to prepare the kids. Around I guess, January to March or so she made alot of comments to the kids saying things like, "count on your Dad for things, your Dad can do these things, he's good at doing these things. And he's doing them for you, not me. "She was trying to, I perceive, make distance between herself and the kids.

Later the father in the family decided to be more direct with the children in preparing them for the patient's death.

He stated, "About three weeks before she passed away I talked to the kids and was trying to tell them that Mommy would likely not ever get out of hospital." The decisions about how to involve and prepare children for the patient's death were particularly difficult for the parents. They often said they didn't know if they were doing the right thing in discussing it with the children, but were doing the best they could to help the children deal with the loss.

Decisions also had to be made about funeral arrangements. In some cases patients themselves had made many of the arrangements and decisions ahead of time.

I- And you said your wife made alot of final arrangements herself?

Husband - Ya, she made them over a year ago, when they told her she had three days. She made arrangements with the Pastor and my brother-in-law, what she wanted. So when she did pass away that's exactly what happened.

The fact that decisions were made ahead of time helped families cope at the time of death. Families reported that having some of these decisions already made eased the stress that they might have experienced if they had to make all the death-related decisions. In other families, the surviving spouse often had to make these decisions. While they were able to do this, these individuals stated that they realized later how exhausted they were from maintaining control and trying to take care of decisions and arrangements.

For families where there was only an older surviving spouse, a decision that had to be made involved living arrangements. Some widows or widowers chose to move in with their children. Others preferred to maintain their independent living arrangements:

Wife- After the funeral I told the kids, I'm going to stay here alone. Don't ask me to go to your place. They wanted me to go to live with them. I said, "No I'm going to try it alone." And I've done pretty good. It's been six months.

In some instances, surviving spouses made the choice to live alone but decided to sell the family home and move into a smaller home. It appeared then, that the changes experienced by the survivors after the death of the patient could be numerous. The day-by-day activities and living arrangements of surviving spouses was a frequently described part of their experiences. Often decisions to make major changes in living arrangements were made at a time of intense grief and stress.

In summary, the death-related decisions involved specific issues that families had to deal with at a very stressful time. There were many of these types of decisions to be made and often they were described as difficult decisions. These decisions were affected by the extent to which families were prepared for the death of the patient. Families often felt alone at this time and lacked the support of the health care providers. They often felt health care providers had not prepared them adequately for some of the decisions that had

to be made, and sometimes felt abandoned by the health care network.

7.8 SUMMARY

A major theme identified in the study was the planning that families were able to do in preparation for the patient's death. The death of the patient was a very clear memory for families, and the order or chaos at that time was part of their memories. There were some parts of the death event that families could not plan for or control. The most significant of these was the way in which the person died. The patient's death could be described as either peaceful or disruptive and the degree of suffering and dignity of the person defined the death. The timing of the patient's death also affected the family's preparation for the event. The death could occur when the family more or less expected it, or it occurred much sooner and more suddenly than they imagined it would. The setting in which the patient died was a significant part of the death experience. Families and patient's who chose to have the patient die at home directly experienced the death scene. This was described in both positive and negative ways. Families were appreciative that the patient died at home as he wished and that he had family support around him, but sometimes were disturbed by a disruptive home death.

The extent to which families were prepared for the patient's death was also related to whether or not they were able to interpret the physiological signs of impending death. When families knew what these signs were and could interpret them, they usually proceeded with planning for death and made death-related decisions. These decisions included calling family members to be present, talking about funeral arrangements, and preparing children for the loss of the parent. In contrast, when families were unaware that death was nearing, these decisions were not made and planning for death did not occur. Often there was more difficulty in reaching family members and in organizing resources to help the family cope. Decisions were made after the death of the patient without there having been as much prior discussion and the weight of these decisions often fell on the bereaved spouse. This part of the terminal care experience included many decisions and was a very demanding for the family. It appeared that the health team was distant and non-specific in their support at this stage of the illness. As a result, families often felt alone and unsure of themselves.

Chapter VIII

THE FINDINGS - EFFECTS OF THE TERMINAL CARE PROCESS ON SURVIVORS

8.1 INTRODUCTION

There were outcomes or responses to the terminal care experience that bereaved families perceived. The sources of the effects were classified into two properties: (a) actual and preferred decision control congruence and (b) loss of the family member. The effects of both of these were described.

8.2 ACTUAL AND PREFERRED DECISION CONTROL - EFFECTS OF CONGRUENCE

Families were able to describe the extent to which they experienced a "match" between how they ideally would have liked to be involved in choices made and the extent to which they were actually involved. There were different types of congruence and incongruence between preferred and actual decision control. There were instances of incongruence between the various participants. In some cases there was incongruence between the family and health care provider or patient and health care provider. There were also examples of incongruence between patients and families themselves. The effects of these kinds of congruence were described by families.

8.2.1 Effects of Patient/Family-Provider Incongruence

The experience classified under this theme referred to the outcomes the family experienced as a result of disagreement with the health provider as to the patient and/or family's role in decision making. Families who felt deprived of information and distant from health care providers saw their decision making role as less active than it would have been if they had known more. The perceived withholding of information by health care providers was described as a way of limiting their decision making involvement. This was sometimes incongruent with the family's preferred involvement:

I- You really didn't feel too involved in the decisions at all?

Husband - No.

Daughter - And I didn't feel good about that.

I- You would have preferred a different type of involvement?

Husband- I would have liked to be in on things, well if they'd said we've got to do this well then we could decide.

One surviving spouse described the effect of her lack of involvement as frustrating and that the effect was on-going:

I- Would you say that the doctors made the decisions about your husband's care?

Wife - Yes, for sure.

I- Would you have preferred to be more involved or is there some way you would have changed that?

Wife - Well I wish I had more information. But they wouldn't tell you anything.

I- Did that affect you at the time?

Wife - Oh yes, I was frustrated and I would ask the doctors at the hospital and they wouldn't say anything.

I- Is it still affecting you in some way?

Wife - Well, I don't know. It's a thing you can't keep on because it's past, but it frustrates me still.

One family described the effect of the patient's loss of control over the decision to have surgery. The patient did not want surgery but, as the patient's husband described, "the doctor pushed surgery because my wife really didn't want to go through with it." The pain that the patient experienced was not described as pain from the illness process, but pain related to the operation.

Husband - I used to ask, where does it hurt? She would say, "It's the operation that hurts. It's not the cancer in the lungs." Her breath was getting shorter. Her lungs were filling up with fluid. She said, "I'm not suffering, it's just the operation that hurts."

The surviving widower described the patient's frustration about the "doctor forcing her and telling her she was stupid because she didn't want to go through the operation". He stated that he believed "she never got over that". The anger expressed by the surviving spouse was notable in the interview as well. He described an argument he had with the doctor about the control of this decision.

Husband - I had an argument with the doctor. We argued about the operation. You see, I went to see our family doctor. I said, "they won't operate on my wife." He said they should. I said, "look doctor you know doctor, cancer, as soon as you touch that with a knife you know what happens." He said, "are you a doctor - what do you know about it?" I said, "I know enough that I've seen enough people

getting operated and a few months after they're gone. I could name you a lot of people that I know. At the age of 40-45, just because they went through an operation. I don't say they wouldn't have died anyway. But they might have gone a little further." So I had quite an argument. I said, "we'll see after the operation doctor, we'll see."

A family also described the control over the decision to proceed with chemotherapy as one of incongruence between the surgeon and patient. The patient experienced a delay in obtaining chemotherapy because the physician delayed his referral to a chemotherapist and wrote a letter that did not recommend that form of treatment.

Husband - When it came to the chemotherapy decision, the surgeon did not recommend that, but we still wanted to explore that possibility. She discussed it with me and we said "he's a surgeon, this guy's a chemotherapist, maybe he might be able to give us some advice." The reason there was a delay in fact, in getting to see a chemotherapist was that they were reluctant to see her because of the medical report that they already had, which was not favorable.

The incongruence between the preferred control over the decision and the delay in the eventual decision was a subtle form of the way in which decisions were affected by the formal authority of physicians. The delay in action related to this decision was stressful for the family and patient as they experienced the progress of the disease.

Two weeks or so later we had a follow-up with the surgeon and he felt she'd recovered very well from the surgery. We asked at that point to have an appointment made with an oncologist and he did send over a note to the oncologist asking for an appointment. We didn't seem to get a response from there. She went back next week to the G.P. and she pointed out that there were already lumps around the neck area.

The lack of power families experienced when it came to acting on decisions was very frustrating for them. Families perceived physicians as wanting to maintain control over medical decisions and arrangements. Sometimes there were delays in these arrangements and families would push for follow-through on the plan. This produced strain between physician and family. In one case a forty-year old patient with a fast -developing second breast tumor waited three weeks for a biopsy of the tumor. At one point the patient's husband attempted to take control of the decision:

Husband - It had been three full weeks. One time I'd said to the doctor that was supposed to do the biopsy, listen, if it has to be done I'll take her to our home town and have it done and we can bring the sample back with us. But he didn't like that comment very much.

The effect of this lack of power over care decisions was frustrating to the family then, and remained so months later. This particular surviving spouse wrote a nine page letter to a media ombudsman because of his continued frustration about this lack of control.

There were no instances when families wished that they had been less active in the decision making role and had felt pressured by health care providers to be involved. All cases of incongruence between family and health care provider decision control involved a frustration on the part of the family at not being allowed a more active decision making role.

8.2.2 Effects of Patient-Family Incongruence

There were also effects identified when there was disagreement between family members as to the process of decision making. The most common form of incongruence over decisions within a family occurred when one person made the decisions and withheld information from others. This was experienced as stressful for other family members and was a burden for the lone decision maker. In one family, the patient made the decision to not seek medical attention after she found a lump in her breast. The family disagreed with the decision, but could not change the patient's mind. The effect of this incongruence on the family was expressed as guilt and regret that they did not take more control.

Daughter- When she told me she had a lump I felt it and it was very small and I told her to go, I thought it was probably just a cyst or it could be so many different things. And of course, getting married and moving away from home, well we moved away from the city, she wasn't complaining, you didn't hear about it after that. She never got headaches, nothing. No illness what-so-ever.

I- So she was able to carry on her normal daily activities?

Daughter - Oh yes, right 'til the day she went to the hospital. She never let on that...

Husband - anything was bothering her.

I- It must have been hard for you in a way though living with her, wondering about it.....

Husband - It was.

Daughter - It's even harder now though, thinking, could we have done something else? Should we have gone to get help? I always wonder if I should have gone to the cancer society and told them the situation, that mom wouldn't go for help. I think I'll always wonder about that.

The control over where the person would die also was an issue of incongruence in some families. One couple had disagreed about where the patient would die. The patient wanted to die at home and his spouse made the decision that he would go to the hospital at the end. Later, he died alone and she experienced regret about this part of the experience.

I- You had wanted to be there when he died?

Wife - Oh yes, I've thought a lot about that. I really felt bad.

In some instances, the belief in the patient's right to make the decisions was supported in principle, but the consequences of those decisions were not always favorable to the family.

Daughter - We took a lot of information from Daddy, he made a lot of the decisions, he was probably as happy as he could have been with that disease. He decided he would be at home and we felt that whatever he wanted we would support.

Wife - I don't think he ever thought that I was as good a nurse as I should have been, I know that, because he told me that. All through my life I haven't been competent enough for him, so this situation made it harder. There was always a proper order for everything and I guess I didn't always see exactly his order. And it was never that I wanted to neglect him, it was just that I didn't always do things right.

Another family described an incongruence in the patient's preferred decision and the decision made jointly by the patient's husband and physician.

Husband - She had got to the point where she was a bit hesitant to go home even though she was ready to go home, after three weeks, so I just kind of insisted on her coming home and so did Dr.A.

After discussing this decision again the husband wondered if the reason for the patient's reluctance to go home was her fear of fluid filling up in her lungs, as this had occurred prior to her last hospital admission. The spouse expressed discomfort at having pushed that decision and at not being more sensitive to the patient's preferred decision control.

The situations of inter-family decision control incongruence were less frequent than family-provider incongruence. It is interesting that in some instances of inter-family decision control incongruence one family member was described as more in liason with the health care provider. The effects of the incongruence were described in terms of regret, guilt and frustration.

8.2.3 Effects of Patient/Family-Provider Congruence

In families where there was congruence between the decision control that occurred and the preferred degree of control, the effects were stated as positive or were seen as a non-issue. In other words, families said that the way they had input into decisions was the way they wanted to be involved. Therefore, things went smoothly and the effects of this were not noticed in any form. Many families were positive about their involvement in decisions and felt well-informed about the care and plans.

In families where the physician was the dominant decision maker and this was the preferred type of decision control, families still valued the information given to them and described themselves as being aware of what was going on. For example, one family described the physician as the main decision maker and they accepted this arrangement.

Husband- And in terms of some of the other decisions, I think that Dr.X. kept us fairly well informed as to what it was he was planning on doing and so on.

Other families saw the decision making control as joint between themselves and health care providers. This was congruent with their preferences as well.

I- Then she started with the pills?

Husband - She was taking pills first, Prednisone and I don't know all the different names. She took chemotherapy after that through the, in her arms.

I- And who made the decision about that?

Husband - The chemotherapy? Well, we talked it over with Dr.X. in the hospital. He told us what he was going to do and we agreed with it.

When asked about the effects of this congruence, families did not identify any outcomes. The effect was a non-issue, whereby the congruence was such that the experience was not noticed.

In another family, there was congruence between how the terminal care experience went and the expectations the family had of how the experience would be. The family was not very aware of the decisions that had to be made. They were very trusting of the physician and relied on him to direct

the plan of care and make the decisions. The one decision that the family was able to identify was the decision to bring the patient home for care and let her die at home. This decision was prompted by the physician and was agreed upon jointly by the couple. Other decisions seem to have happened without any discussion. The spouse felt informed about the treatment and had good rapport with physicians and public health nurses. The family had a high degree of control over the last three years as they cared for the patient at home. The control was described in terms of the time, care privacy and individualized experience that the patient had with the family at home. This was described in a matter-of-fact but positive way.

I- It sounds like the way you were involved in her care was the way you wanted to be. Would you have preferred it any other way? Would there be anything you would change?

Husband - Well, I thought we did it as good as we could.

The effect of congruence between provider and family decision control was an important finding. The fact that the effects of this congruence were either seen as positive or were not noticed indicated that the family did not experience additional stress related to this issue.

8.2.4 Effects of Family-Patient Congruence

The congruence over decisions within the family was remembered in a positive way. Many families used phrases such as "if the patient was happy, we were happy", or "if it's what he wanted, then it was his decision." The closeness among family members that came from this congruence was described as well.

I - I would like to go back to the idea that the decision making control that you had was close to the control you preferred, is that affecting the family unit now in anyway?

Wife - Well I've certainly been aware of a very supportive daughter.

Families also expressed positive feelings about agreeing with the patient's wish of where to die. For example:

I- You were glad she made the decision to come home to die?

Husband - Oh yes. She was happy, she wanted to die in her home, oh definitely.

In families where there was joint discussion and decisions were made as a family, the families remembered the support and value of this exchange.

I- So the main decision maker was David, but there was alot of joint discussion.

Daughter- That's right, but I'd say David was.

I- And would you have preferred a different kind of decision making in all of this?

D- No, no I don't think so because David was always talking with my brothers, always on the phone, always discussing it. And one time they were all here together and it was a joint decision, but David was the one that threw out the ideas. And without the support of my brothers, I don't know what would have happened.

The congruence between preferred and actual involvement in decisions within the family was an important part of the terminal care experience. The effects of this congruence were remembered as a good feeling about the care the patient received, a feeling of closeness in the family, a sense of support among family members and a respect for the patient's preferred control.

8.3 EFFECTS OF THE LOSS OF A FAMILY MEMBER

The other kind of effects families experienced were due to the death of the patient. These were effects that were related to the general loss experience and were not described especially as a result of the decision making part of the event. There were definite effects on the families' health, which supported the literature on the impact of death on the bereaved. Families reported fatigue as the most common symptom and described the effect of the experience on their energy and sleep patterns.

I- Has the experience effected your own health in anyway or your family's health?

Wife- I was so tired, especially the last week. I would come home and fall asleep sitting up. And yet at night I couldn't sleep. And when he was home I couldn't sleep. I had to finally get sleeping pills from the doctor.

Others talked of the fact that they were having difficulty sleeping after the patient's death but were able to carry on activities with much less sleep.

Husband - I could not sleep very well. I would go to bed but I wasn't tired. I'd go to bed usually

eleven thirty or so and I'd be awake about two or three o'clock. And I'd be awake the rest of the night and this carried on, a month or so. Yet, somehow or other, I felt that somehow I was able to carry on, I didn't need that sleep as much.

Families experienced exacerbations of chronic conditions such as diabetes when they went through the terminal care experience. Surviving spouses were diagnosed with new conditions as well. For example, family members reported being diagnosed with ulcerative colitis, hypertension, and ulcers. Families also described symptoms such as heart palpitations, chest pain and chest tightness, weight loss, weight gain, stomach problems, and back pains during and after the patient's illness. A surviving daughter was experiencing a difficult pregnancy and there were fears that she would have a miscarriage.

These families described emotional health changes as well. Some talked of the depressions they experienced and the reliance on alcohol and sedatives. After the death of the patient, surviving spouses were reluctant to take on added responsibilities at work and tried to avoid undue stress.

Some families experienced anxiety about getting cancer themselves or fears that their children might "inherit" the same disease as the patient.

Daughter - You see, I have a history of health problems and tumors too, which is very, which I am very concerned about. I had a pituitary tumor which was radiated about twelve years ago. I go for tests every year because it could reoccur. Although it is a benign thing, but I've had that. And I've also had a change of a mole on my leg

which was removed and they found there were some atypical cells and had to remove some more. My history makes me I guess prone to cancer, so I am worried about this.

The children of deceased patients also experienced health changes. One fifteen year old boy was hospitalized for "nerve problems" when he was told his mother had "three days to live".

Son - I'm just like my Dad, keep my feelings in. Except when they gave her three days to live I was sick with nerves for three weeks.

I- With nerves?

Son- I wasn't eating, wasn't drinking.

Husband - They couldn't figure out what it was. They took tests.

Son - They never told me what it was. Once I started eating it was okay. For awhile I wasn't eating any solid food at all.

Husband - I had to go see him every night.

I- You were in the hospital?

Son- Ya, one week for my knee surgery and three weeks for my nerves.

Children experienced a number of "accidents" as well during the illness of their parent. For example, one thirteen year old girl broke her arm, one girl sprained an ankle, and a boy tore a cartilage in his knee. Other children described eating problems and symptoms of chest tightness. The emotional impact on children was described as significant as well. Parents talked of crying episodes, fears of being alone, feelings of guilt and accountability for the patient's death, and loneliness. One fourteen year old girl

talked of her fears at night. She stated: "I just get scared that, I don't know, it's confusing...It's just like all of a sudden everything can change and I don't know, scare me."

Families also experienced changes in roles as a result of the death of the patient. Surviving spouses felt the "weight" of responsibility now that they were alone.

Husband - It was hard to deal with a lot of things at first. For example, I had been doing most of the housekeeping when Margaret had decided to go back to University. But now I would go and cook a meal and do the dishes and I found it was very hard because all of a sudden I didn't have the back-up. In the past, before if some evening I said, gee I really don't feel up to it today, Margaret would step in. And now I didn't have that backup. And it was really bothering me for awhile.

I- Weightier.

Husband- Ya, all of a sudden you feel this burden, gee whiz, I've got to be doing this all the time and there is no one who's going to give me any relief in this regard. But then this carried on for awhile. But eventually you become resigned to it, it's just part of your normal duties. I don't feel that way anymore, but at the time it was really bothering me. Gee whiz, here I am stuck with this and I haven't got anyone to do it with me.

The other effects included changes in living arrangements if a surviving spouse went to live with children or changes in closeness and activities shared by families. Many families reported feeling closer to each other.

On the other hand, marital conflict sometimes occurred during the illness or after the death of the patient.

Daughter - It's mainly effected my relationship with my husband where I feel he did not give the support he should have. He had to go to a conference in New York, and it was the night my Dad died and he was ready to go and I said my father's dying, I can't even come home to be with the chil-

dren. And if you really think it's important to go get a babysitter to come and she can sleep over. And he did. And at eleven o'clock he made the decision the babysitter should go home and he should stay home. But I guess he didn't believe my father was going to die. But he wasn't very much involved. I said, "look, he's been unconscious for two days.." So I have tremendous hostility now and it just has to be worked out I suppose. And that's the main thing. How else it's changed me, I don't know. I think it's mainly my relationship with my husband has really suffered a great deal.

In one family, a surviving spouse felt sad and unfinished about her relationship with her husband because of the problems in the marriage. She stated at the end of the interview, "It will always bother me that I just wasn't right for that guy."

In other families the marital relationship between patient and spouse was strengthened by the experience. A widow remembered her husband's words when she cared for him at home, "he said, you're the best nurse I ever had."

Another widower described his relationship with his wife: "In terms of our relationship, that time was very valuable to both of us despite the suffering. I think we grew a lot closer to each other over the time, we would have missed out on otherwise."

The effects of the experience were varied and intense. There were definite health changes experienced, emotional stresses and effects upon family relationships.

8.4 SUMMARY

In summary, the effects of the terminal care experience on survivors were described from two perspectives: the degree of decision control congruence and the response of families to the death of the patient. In the first instance, incongruence between preferred and actual involvement in decision making had more impact on the families. The effects were stated as guilt, regret and frustration about the decision making experience.

The effects of congruence between preferred and actual decision making involvement were seen very positively when there was congruence within the family. Effects of congruence between provider and family were not perceived or articulated too specifically by families. Rather, there was a general feeling that "things had gone as well as could be expected".

In terms of the effects of the family due to the death of the patient there were notable health changes, emotional problems and family interaction changes. These findings supported the research done on the health effects of the death experience on the bereaved.

Chapter IX

DISCUSSION AND RECOMMENDATIONS

9.1 INTRODUCTION

The purpose of a theoretical framework is to provide a basic conceptual scheme that organizes facts in a systematic way and permits an understanding of events. The theoretical framework that emerged from the study of families' perceptions of their participation in terminal care decisions provides a description of this experience. The framework includes categories and properties which describe the components of family participation in terminal care decisions.

The study was a factor-searching one designed to utilize real world data to generate theory. This type of study belongs to the "context of discovery" rather than the "context of verification" (Glaser & Strauss, 1968). The result of this type of study is "a bit of theory, in the form of conceptual description or in the form of a set of categories related to one underlying dimension" (Diers, 1979, p. 118). This research represents a first step, that is, naming and defining categories and concepts. Hypotheses have resulted about the relationship of these categories to each other. The next step of research in this area would then be to test

the reliability and validity of the categories developed (Diers, 1979).

The discussion of the theoretical framework is intended to integrate and explain the categories developed. The discussion also integrates the work of other researchers and relevant literature in the field. The discussion is organized around the major categories:

1. Decision Control
2. Information
3. The Meaning of the Situation
4. Patterns and Characteristics of Family Interaction
5. Planning for Death
6. Effects of the Terminal Care Process on Survivors

The chapter concludes with a series of recommendations related to how the theoretical framework has implications for the health care delivery system. Suggestions for further research in the area of family decision making participation in terminal care situations are included.

9.2 DECISION CONTROL

Decision control was an important category that was identified in the study and was central to the terminal care experience. The literature that describes and defines decision making was helpful in understanding this category. According to Schaefer (1971), the nature of decision making is the art of choice following deliberation and judgment. To make a de-

cision, three conditions must be fulfilled: freedom, rationality, and voluntariness. A person must be free to make a choice and therefore, have authority over that choice. The person must also be able to deliberate about alternatives to arrive at a judgment. And finally, the individual must make the choice, which is the art of volition. The extent to which these three conditions are present in the terminal care decision making process effects who has control over the decisions.

The study found that the most common type of decision making that occurred was medically controlled decision making. This was especially true if the decisions depended upon scientific information and knowledge related to the disease, interpretations of laboratory results and medical treatment options. Physicians were dominant in decisions most often when the patient was hospitalized frequently or for extended periods of time. Martocchio (1982) also found that the number of hospital confinement days affected the roles played by patients, families and health care providers. Health care providers held more power in the hospital and patients and families were expected to conform to the rules of the hospital. The setting within which care occurred therefore, was an important factor in determining who had decision control.

Vertinsky et al. (1974) also found that once a physician was contracted for care, the decision process became one in which the physician's preferences often dominated. One rea-

son for this was the difference between health care providers' and families' knowledge about the disease and treatments. Therefore, patients and families were often limited in their abilities to consider alternatives because they were unaware of all options and the consequences of the alternatives. The rationality available to patients and families in decision participation was then restricted.

Families and patients had more control over decisions if care was given in the patient's home. The decision to move from the hospital to home setting was often described as a "turning point" in terms of decision control. A shift in power over decision making would occur from health care providers to patient and family when the patient went home. Glaser and Strauss' (1968) study of the death experience found that where a person chose to die was important to the control over decisions made.

One property of decision control that was identified involved power and authority over decisions. All interactors possessed different types of power and used different means to maintain or secure control over the decision making process. Physicians clearly held the most formal legal authority. Physicians could withhold information as a way of maintaining control over decisions. Withholding information precluded informed decisions, and interfered with attempts to reach an informed decision. Oken (1967), in a study of cancer patients, found that there is a strong and general

tendency to withhold from a patient the information that he has cancer. Almost ninety percent of the total group surveyed reported that their usual policy is not to tell the patient he has cancer.

In contrast, in this study there appeared to have been a shift in the general tendency of physicians to tell patients their diagnosis. Physicians generally told patients and families that the patient had cancer or named the specific diagnosis. However, a continued dialogue about the diagnosis, the prognosis, treatment options or a collaborative decision making process did not occur. It would seem then, that while a shift in physicians' willingness to disclose the cancer diagnosis has occurred, a shift in decision control is not evident.

Families also experienced the physician's power in the interactions that occurred between them over decisions. They feared angering the physician and felt a need to maintain good relations with him. This anxiety usually resulted in a more passive, compliant interaction with the physician and families said they sometimes went along with decisions that they did not really like. Interpersonal conflict over control could also be seen by families as a lack of caring on the part of the health care provider and a lack of respect for the families' beliefs and preferences.

Families also described their lack of power and authority. This was often discussed in relation to their lack of

information about the situation. Information and knowledge were identified as the major source of power and authority.

Nurses were described as having some power and authority over certain decisions, but mainly functioned by offering their information to the family. In this way the nurses gave away their information quite freely and thereby increased the decision making power of the family.

9.3 INFORMATION

Information was an important source of power and control over decision making. Information included facts obtained through observations, discussions and readings. Health care providers were seen as the primary information source and controlled the information available to patients and families. Families also identified the importance of having enough information. There were no instances where families felt they had too much information. They related many examples of how they tried to obtain more knowledge or more complete and detailed information from various sources. A lack of information contributed to families' feelings of powerlessness. Conversely, the more information families had, the more in control they felt.

The quality of communication and interaction between families and health care providers was also related to the information exchange process. When families had good rapport with health care providers, information exchange occurred

quite smoothly. In contrast, when relations between health care providers and families were poor, information flow was obstructed. Martocchio (1982) found that the interpersonal exchange between participants in terminal care situations was central to the quality of information flow. She also found that access to information was an issue for families and that if one source was not seen as easily accessible, families would search out other sources instead. Martocchio described the anger and frustration families experienced when information was not forthcoming. Most interactors believed that physicians possessed information that was not made available to anyone else...the immediate search for further information by patients or family members and other interactors, could result in direct questioning of the physician who then may or may not reveal information, restarting the cycle (Martocchio, 1982).

The control of information also depended upon the patients' and families' abilities to access information. The exchange was related to the interpersonal relationships between participants and whether or not family members knew how to ask questions of health care providers and if, indeed they knew what questions to ask. The imbalance in power between health care providers and families and between physicians and families in particular, was a factor in determining the communication and concomitant free-flow of information between these two parties.

Families often turned to friends or relatives who may or may not have formal health training for information and interpretation of facts. Martocchio (1982) also described how more frequently, patients and family members turned to nurses or other sources such as other nursing personnel or other hospital employees, visitors and other patients. In these relationships the balance of power and authority was more even and interpersonal communication less threatening.

Another issue that arose in conjunction with the importance of information was the notion of trust. Families often stated that when they lacked information or complete understanding of decisions they had to trust the health care providers to a greater extent. Trust, then, was part of decision control. In instances where families had more information and knowledge about a decision they would more actively participate in the decision. In cases where families had little information or understanding, decision control was often given to the physician with a strong measure of trust. For example, decisions about surgical interventions were frequently medically-controlled decisions that families reported trusting to the physician.

Trust could also be fostered as a result of information exchange. In situations where health care providers communicated easily with families and families experienced a feeling of being "well-informed", they reported a high degree of trust in the health care provider.

Information also varied in the kind and form of facts available to families. Generally, the more direct and complete the information given, the more clearly it was understood by families. Ambiguous phrases were, on the other hand, frequently misinterpreted by family members. This information property was an especially important link to the next category that was identified - the meaning of the situation. If information was given in vague, indirect ways, families were more likely to arrive at various meanings of the situation. Confusion and conflict sometimes occurred between family members or between health care providers and family when participants had different understandings of the circumstances. The study differentiated information from knowledge. Information involved the acquisition of facts; whereas knowledge referred to the interpretation and meaning given to the facts by the different participants.

9.4 THE MEANING OF THE SITUATION

Families could interpret facts presented to them a number of ways. In addition, their interpretations resulted from a synthesis of their personal belief systems, their understanding of signs and symptoms, and the degree of hope that they had in the situation.

This category was important to decision control. Families identified personal definitions of health and illness that affected their interpretations of physical symptoms. The ex-

tent to which signs of disease fit their personal definitions of illness determined whether or not they made the initial decision to seek medical attention. In some cases, the symptoms were not viewed as unhealthy, so treatment decisions were delayed. The outcomes of patients' illnesses could well have been influenced by this important decision. It was noted that often the signs that were ignored or were not acted upon promptly were signs or symptoms of cancer frequently advertised by organizations such as the Canadian Cancer Society. This suggests that simply knowing facts is not sufficient to prompt health seeking behavior. The chain of "facts-knowledge-health behavior" is complex and health care providers cannot assume that presentation of information will necessarily result in health behavior changes.

Another property within this category was the reaction of families and patients to events and facts. Of particular importance to decision making were the reactions of families and patients in the early diagnostic stages of the illness. Families often described the shock and disbelief of hearing a diagnosis such as "leukemia" or "cancer of the bowel". They stated that in the early phase of the illness they were frequently "swept along" with the rapid sequence of decisions made by physicians because they did not realize what was happening. They reported feeling too numb to question or discuss alternative choices. Later on in the illness, families stated that they regretted not being more involved in the early treatment and care decisions.

Weisman (1979) referred to the early state of diagnosis as the "existential plight stage". This occurred as families experienced the shock of hearing the diagnosis. Weisman (1979) describes this stage as approximately the first hundred days. The way in which patients coped in this early stage was often a peak reaction and often indicated how they would handle the rest of the disease course.

The difference between knowing that the patient had cancer and identifying the patient's situation as terminal was another property that emerged. Families could identify or label the patient as "terminal" at different times. The meaning of the situation and decisions made were very much affected by the recognition and awareness of the patient's approaching death.

Awareness of physical deterioration of the patient was one way families realized that the patient's condition was terminal. Sometimes families knew this, but their understanding of the dying trajectory did not match what actually occurred. Glaser and Strauss (1968) describe the different dying trajectories that occur. The degree to which the health care provider discussed this trajectory and interpreted signs to the family seemed to be important to the accuracy of the dying trajectory the family imagined.

Weisman (1979) talks of the importance of psychosocial staging in helping patients and families cope with the cancer experience. This concept is based upon psychosocial ef-

fectiveness, spread, cellular differentiation, and so forth. Weisman (1979) identified four psychosocial stages, which could be considered in conjunction with, if not parallel to, four clinicoanatomical stages:

1. Existential Plight
2. Mitigation and Accomodation
3. Decline and Deterioration
4. Preterminality and Terminality

It appears that in each of these stages, there is a level of awareness that patients have about the disease, based upon what they are told and how they interpret the experience. Initially, the patient is shocked by the news of the diagnosis and patients report that they imagine death as a real possibility - an existential plight. The second stage involves a dissipation of stress and a regain of some autonomy and sense of stability. The later stages refer to decline and preparation for death. Weisman (1979) writes of the differences in patient's awarenesses during these stages. He describes different types of awareness that range from denial to more open forms of awareness contexts. The interactions between participants in these stages are central to the understanding that patients have of their condition. While Weisman describes these stages with specific reference to patients rather than families, it would seem that the general psychosocial stages that families experience might be similar.

The lack of knowledge of the terminal quality of the patient's illness has been described a number of ways. Kubler-Ross (1969) talks of this as a type of denial. Weisman (1979) refers to this as middle knowledge. Middle knowledge means knowing and not knowing at the same time. Middle knowledge is not found only in very sick patients according to Weisman, but may occur in potential or actual survivors who cannot believe death is near.

Part of the difficulty for families in identifying the terminal phase of living-dying is that this phase is often not precise. Rioch (1961) describes this stage as the time when the dying person begins to withdraw into himself in response to internal body signals that tell him he must now conserve his energies. Many writers (Glaser & Strauss, 1968; Kubler-Ross, 1971; Garfield, 1978) describe the disengagement and separation from the patient by others. This may occur days, weeks or months before the person dies. It is partly a gradual separating effort on the part of the patient and others as a beginning "letting go" phase.

Psychologically, death occurs when the person accepts his death and regresses into himself (Garfield, 1978). Biologically, death occurs when the organism as a human entity no longer exists. There is neither consciousness nor awareness, such as in the case of irreversible coma. Finally, physiological death occurs when vital organs such as heart, lungs, and brain no longer function (Garfield, 1978).

The importance of these types of death is that they occur at different times and can generate stress and confusion for families. It appears that interpreting these different types of death to families would be helpful to them in understanding the situation.

The notion of hope was another property that was related to the families' understanding of the situation. Hope was described as essential to survival. This property involved the expectations and anticipations of the family and patient. These expectations were very much part of the meaning of the terminal care experience. Hope was related to how information was heard by families and explanations could be said to also give families hope.

The hope in experimental trials was often mentioned by families. In these instances the notion of hope involved a feeling of actively trying to confront the disease rather than passively succumbing. These families knew that the prognosis was often very poor, but needed the focus and activity associated with the hope in experimental trials.

According to Stotland (1969), hope is a learned response, augmented by the example of supportive and successful others. Weisman (1979) describes hope as an intangible, immeasurable, and very real sentiment. He has observed that most cancer patients do not depend on hope alone, nor do they hope exclusively for recovery, extended survival, or return to previous ways of life. Hope is designed to see

people through adversity, because it is a character trait, not because it can be strategically generated or discouraged (Weisman, 1979). This literature presents an interesting conceptualization of hope. Hope is identified as an element in coping with a terminal illness. It is described as a personality trait, rather than an independent element developed within a particular context. Weisman's (1979) descriptions of hope indicates that the hope cancer patients have, depends not so much upon goals, but rather upon self-concept. This observation was also noted in the study. Initially the researcher listened to the situations described and considered how hope was described, whether the hope held onto by families was "realistic" and congruent with the facts presented by the health care providers about the disease prognosis. The researcher's reaction to descriptions of hope were in terms of the accuracy of this quality in relation to the disease prognosis. A more thoughtful analysis identifies hope as important to the kind of person the patient was. For example, comments such as "she was a fighter", or "she just couldn't lie down and die", describe the kind of person that the patient was and the hopeful trait the patient possessed. Therefore, the hope evident in aggressive experimental trails or toxic treatments was an important part of the patient's self-image. Most families who chose aggressive treatment approaches expressed no regret at having pursued this pathway. It may be important for health care providers

to look at the role hope plays in a family and to understand the way in which hope may relate to the self-image of the patient. For patients with a strong hopeful trait, ways of fostering this hope may be central to the dignity the patients' experience in dealing with the terminal illness. For others, hope may be a lesser characteristic, and efforts to foster this or act in support of this trait may be inappropriate. There is much more to understand about hope in relation to patients' and families' terminal care plights. However, it appears that hope is an important property that contributes to the meaning of the experience and the ways in which families cope.

The decisions families and patients make about the illness episode are also affected by this characteristic. Numerous decisions occur within this context. What families believe about health and illness is one aspect of their understanding. How they react and interpret events is a second part of the meaning they give to the situation. The ways that families and patients come to know that the disease is terminal is an important turning point in their awareness of their circumstances. And lastly, the hopeful sentiment in the scenario plays a principal part in determining the meaning of the terminal situation.

9.5 PATTERNS AND CHARACTERISTICS OF FAMILY INTERACTION

The study identified patterns or tendencies of behavior between family members as they interacted in the decision making process. The patterns were also characterized by certain qualities of behavior between individuals. These patterns and characteristics were related to the information that families had about the terminal care situation and the meaning they gave to the experience.

The patterns of family interaction could involve one person as the primary decision maker or could involve a number of individuals in the decision making process. The flow of information largely determined the pattern of decision making interaction. For instance, in families where one person had the majority of contact with the physician, and was then the family source of information; the pattern of decision making tended to involve that one person. This pattern could create conflict or strain in the family if other family members were affected by the outcomes of the decisions, or if they wanted more input into the decisions.

Joint decision making patterns were the least conflict producing and families generally reported decision making as a collaborative supportive process. This pattern could involve negotiated decision making or an "understood" decision process. The "understood" joint decisions occurred most often in families in which the husband and wife had lived together for a number of years and there was an awareness of each other's preferences.

In some instances interactions were described as interactions of indecision. This decision making characteristic often occurred in the joint decision making pattern and resulted in delays in final choices. A lack of information was often noticeable during interactions of indecision. Also, when family members had different interpretations of the terminal care situation, indecision more frequently occurred.

This characteristic of decision making was also described by Degner et al., (1981) as "waffling". These researchers identified one way that families could participate in waffling by first giving consent to treatment and then withdrawing it. It was also noted that families described interactions of indecision as stressful. The stressful nature of this characteristic of family decision making interaction was also identified by Degner et al., (1981). They found that waffling was a state of vacillation that could produce difficulties for many of the participants.

Fortuitous decision making was another characteristic described by families. These types of decisions were less frequent but were seen as very important. The decision was described as fortuitous when the decision was the way families' would have preferred the decision to be if they had made the choice deliberately. In these cases, there had usually been no discussion about their preferences or the disease itself; therefore, when the decision "happened" fam-

ilies were relieved it had occurred the way they preferred. In some cases these decisions could have been prepared for and planned. It would be important then, for health care providers to discuss preferences that families may have about decisions, so that these decisions do not rely on good fortune, or conversely, that "unlucky" decisions do not occur. The most important of these decisions seemed to be where the person would die, and who would be with the person at the time of death. This was often the most frequently discussed decision, the effects of which, remained with the family members after the death of the patient. These decisions also created the most guilt and regret if the decisions were not the way the patient and family would have preferred.

The last characteristic identified were planned/organized decision making qualities of interaction patterns. This characteristic occurred most frequently in families where the pattern of decision making involved one person. It also occurred when families described themselves as "well-informed" and when they felt in control of terminal care decisions. This form of decision making was expressed very positively and gave families a sense of care and order in the decision making process.

9.6 PLANNING FOR DEATH

A stage of the terminal care experience that was especially important in terms of family decision making was the planning for death phase. The preparation and organization of preferences and decisions at this time was particularly stressful and often resulted in the most pronounced after-effects for families. The extent to which families were able to plan for the patient's death depended upon the amount of information they had, and their knowledge of the fact that the death was imminent. Death-related decisions, such as funeral arrangements, or who would be called at the time of death, were important to family members. Also, the "where to die" decision was often central to the family's experience. An understanding that death was going to occur allowed families to discuss and make this decision. The awareness or labelling of the patient as terminal, did not always occur in families and also did not always happen at the same time for all family members. This finding was also described in Martocchio's (1982) study of terminally ill patients. She differentiated between a patient with a high risk of dying and a dying patient. Patients were labelled as having a high risk of dying by virtue of their diagnostic label, guarded prognosis, or their observable physical deterioration or non-remitting progressive symptomatology. They were labelled as dying patients when there was common agreement that death was inevitable within a fairly predictable period of time (Martocchio, 1982).

It was the label of the patient as "dying" that was most inconsistently applied. Families might know that the patient had cancer and had been given a poor prognosis. They therefore knew that the patient was at a high risk of dying. However, families often did not recognize or know that the patient was dying. They reported often not being told that death was nearing or that the various symptoms indicated physical deterioration. This factor influenced the death scene that occurred as well. The scene could be planned and calm or chaotic and stressful depending upon the timing of death and the awareness of the family. There were also elements that were outside of anyone's control. For example, the patient's death could be described as peaceful or disruptive. The way the patient died was beyond control. Families who chose to have the patient die at home were more frequently present at the death scene and were more likely to experience a disruptive death.

Families also felt alone and abandoned by the health care system when patients chose to die at home. The arrangements such as removal of the patient's body, signing of the death certificate and availability of health care providers were loosely arranged and sometimes conflict-producing. There were often gaps in the organization of procedures to follow after the death of the patient, and families usually had no health care provider available to them at the time of death or afterward to support them through these decisions. This

aspect was the most noticeable gap in the delivery of health care support to terminally ill patients.

The numerous decisions made during this stage, the vivid memories of the death scenes, the significance of the dignity and control that patients had over their own death experiences were all very important events that families described. The effects of decisions made within this phase were the most intense and long-lasting.

9.7 EFFECTS OF THE TERMINAL CARE PROCESS ON SURVIVORS

The terminal care process had profound effects upon families. The effects were described as originating from two sources: (a) the congruence between preferred and actual decision control and (b) the death of the family member.

The effects of incongruence between preferred and actual decision control were more noticeable to families than effects of congruence. This was particularly true when the incongruence occurred between health care providers and families. Frustration, anger and guilt about loss of decision control were commonly mentioned. These feelings remained with families to a degree months after the death of the patient. Families often cited the control and lack of information by health care providers as a factor that limited their decision involvement. Decisions that were made by health care providers without respect for the patient's contrasting wishes often left families with a sense that the health care

provider "did not care" about the patient. They also saw the negative outcomes of these decisions as very detrimental to the patient. Incongruence between health care providers and family often brought the family closer together, but obstructed communication between health care providers and family. Sometimes the conflict resulted in families changing physicians as a way of re-structuring the decision control.

Families also experienced incongruence among themselves and in particular between the patient and other family members. The effects of this type of incongruence were experienced as guilt later and families regretted conflict about some of the decisions. More frequently though, families would support the patient's right to have the primary decision control; therefore, there would be congruence between preferred and actual decision control. However, these families sometimes were not happy with the actual decisions that were made by the patient or the way in which the decisions effected them.

The effects of congruence between preferred and actual decision control were not noticed as important when it occurred between health care providers and families. It was rather, a memory of how smoothly matters happened. Congruence within a family was described in positive terms though and was remembered as a supportive, mutuality within which decisions occurred. The family was left with a feeling that they had supported and respected the patient through this

time. These positive feelings were important parts of the families' memories.

The effects that were described as a result of the loss of the patient were very specific and very common. Families experienced periods of grief and loneliness, physical health changes, psychological health changes and alterations in energy levels. These findings are certainly congruent with the health changes described by numerous researchers in studies of the bereaved (Lefebvre, 1978; Glick, Weiss, & Parkes, 1974). Parkes (1972) studied cancer patients and showed how in some cases, somatic illness follows a psychological stress, especially a loss or death. Dewi Rees (1972) also reported that various illnesses are found to be more frequent among survivors than in matched comparison groups.

Families also reported feeling abandoned by health care providers once the patient died. Home care resources were removed, physician contact ended, public health nurses did not visit again; and families felt alone. Many families identified a need for bereavement follow-up or bereavement groups.

Many described the extreme change in daily activities as a stress after the patient's death. Often during the illness episode families had been actively caring for the patient at home or were busy visiting at the hospital and taking care of family arrangements. The picture was one of constant activity, movement and responsibility. After the death of the

patient there was a sudden vacuum in the daily pattern of survivors. All of a sudden the routine that they had been committed to was gone. They no longer had to get up each day with plans to go to the hospital or care for the patient.

The survivors did say that they still had many responsibilities and the weight of these was often felt more directly when the patient died and they realized that now they alone were the parent or head of the household. The change in roles that accompanied the death of the patient was perceived more clearly when the patient died, even though the role changes may have been gradually occurring during the course of the illness. The literature on role theory describes the interactional changes families experience as roles are altered in response to normal developmental and maturational changes or crisis events. Feldman and Scherz (1967) see the family as operating through roles that shift and alter during the course of the family's life. Almost all writings in relation to role theory describe the dynamic or changing quality of a role (Bierstedt, 1963; Coe, 1970). The pressures experienced by family members and the energy required by them to take on new roles and new responsibilities when a family member dies, are significant.

The preparation that families had for the death of the patient also seemed to be important to their feelings afterward. Families who expected the death of the patient at the

time that it occurred had usually had the opportunity to say good-bye to the patient and had, in some cases detached or prepared themselves for the loss. In other instances, the death occurred abruptly when the family did not expect it, or at a time that the families described as "too soon". The shock and suddenness of the loss often left these survivors in more noticeable distress after the death. These survivors reported more periods of depression, alcohol abuse, sleep problems, and physical symptoms.

The literature on bereavement sheds some light on these reactions. Weisman (1979) indicates that preparation or at least having an opportunity to exchange and express ideas and feelings may ameliorate some of the painful loss that will follow. Glick, Weiss, and Parkes (1974) found that forewarning of a husband's death helped some widows recover and find new resources earlier than if the death occurred suddenly. Weisman (1979) also postulates that better anticipatory resolution may not only reduce prolonged bereavement, but may eliminate secondary physical and psychological aberrance later on. These writings together with the findings of the study indicate the importance of bereavement preparation and follow-up. Bereavement is erroneously regarded as a thoroughly natural phenomenon, hardly a process, that usually disappears after a time without special attention (Weisman, 1979). According to Volkan (1970), abnormal grief and delayed mourning are well-recognized manifestations or prob-

lems in relinquishing a significant other. There appears to be a definite need for bereavement counselling for survivors from both preventative and therapeutic perspectives.

Another issue that was identified in the study related to bereavement, involves the unresolved problems that existed between the patient and family. Weisman (1979) found that past regrets, pessimism, and marital problems prior to cancer do make a significant difference in coping effectiveness. Families who experienced marital stress and interpersonal conflicts, who may have stayed together partly because of the illness, expressed guilt and sadness after the death. This issue is something health care providers could be alert to and also raises questions about the role of the health care provider in these situations: Are there ways of helping these families work through these problems or reach some sense of resolution before the patient's death? How do health care providers assess the family interaction patterns, and how does one identify the conflicts that are more deep-rooted in a relationship versus those that are illness-related? And later, as part of the bereavement phase, how do health care providers help survivors work through these feelings of regret, guilt or anger?

The impact of the death of the patient on a family was multi-faceted and resulted from many aspects of the relationship. The role of health care providers and nurses in particular, could be better directed to prevent the complications of loss experienced by survivors.

9.8 IMPLICATIONS FOR HEALTH CARE DELIVERY

The theoretical framework that emerged from the study identified a number of weaknesses in the health care delivery system in meeting the needs of families in terminal care situations. Some of the difficulties have been identified in other studies as well. Therefore, the implications for health care delivery that the findings in this study suggest, are congruent with previous research (Parkes, 1972; Weisman, 1972; Glaser & Strauss, 1968). The problems relate to the process that participants are involved in during a terminal illness. There are also outcomes that are unfavorable as a result of difficulties in the drama that unfolds when a person has a terminal illness. The following recommendations are the most important suggestions that are evident from the descriptive theoretical framework of the study.

1. That the type of decision control preferred by patients and families be identified by health care providers as early on in the illness episode as possible.
2. That patients and families be given information about the illness experience clearly, directly, and thoroughly.
3. That interpretations of information be clarified and discussed with patients and families to ensure accuracy of message transmission.

4. That decisions to be made are identified and discussed with patients and families in time for an informed decisions to be made.
5. That health care providers assess family interaction patterns and characteristics and identify potential stresses in these interactions.
6. That health care providers prepare patients and families for decisions that need to be made when the patient dies at home.
7. That health care providers facilitate organization and dignity in the care of the deceased, particularly when the patient dies at home.
8. That health care providers help families identify the dying phase of the illness to permit preparation for death.
9. That health care providers provide bereavement counselling for families who have experienced the death of a family member.
10. That health care providers be prepared to be more active in the early diagnostic stages of decision making with concern for the preferences of the patient and family and with a willingness to review and explain information.
11. That the health status of family member be assessed and attended to in a preventative and therapeutic sense during and after the illness episode of the patient.

12. That consumer organizations facilitate education about informed consent and the rights of patients in health care decisions.

9.9 RECOMMENDATIONS FOR FURTHER RESEARCH

1. Research to validate the categories identified in the theoretical framework of the study utilizing a larger sample.
2. Research to identify the extent to which patient and family decision control preferences remain constant over time, from pre-illness stages through the terminal illness experience.
3. Research to identify the experiences of patients as well as families as they are experiencing the decision making process in terminal illness situations.
4. A quasi-experimental research study to explore the effects of bereavement counselling and anticipatory grief counselling on survivors.
5. A descriptive study to identify the notion, hope, and the role hope plays in the terminal care experience of families. Particular focus would be on the relationship of hope to information, the meaning of the situation and the effects of the terminal care process on survivors.
6. Research to develop and refine a tool to assess the health and functioning of families.

7. Research to further evaluate the reliability of using multiple respondents as opposed to individual respondents to obtain data.

Appendix A

TABLE 1 - TIME OF INTERVIEW AFTER DEATH

Time After Death (months)	Number of Families Interviewed
0 - 2	1
2 - 4	1
4 - 6	4
6 - 8	2
8 - 10	<u>2</u>
	N = 10

Appendix B

TABLE 2

Family - Age and Sex Distribution

Family	Family Composition	Sex Distribution		Age Distribution						
		M	F	1-10	11-21	21-30	31-40	41-50	51-60	60-
1	husband/wife/children	4	2	1		2	1		2	
2	husband/wife/children	2	4			1	3			2
3	husband/wife/grandparent	4	3	1	1		1	2		2
4	husband/wife/child	2	2	2			2			
5	husband/wife/child	2	4				3	1		2
6	husband/wife/child	1	2					1		2
7	husband/wife/grandchildren	6	6	1	1		3	5		2
8	husband/wife/child/sister	3	4	1	2		1	3		
9	husband/wife/child	1	3		2			2		
10	husband/wife/child	3	2		3			2		
N = 10	N = 60	N = 28	N = 32	N=6	N=9	N=3	N=14	N=16	N=2	N=10

Appendix C

TABLE 3 - ETHNIC BACKGROUND

Ethnic Background	Number of Families
British Canadian	3
German Canadian	1
French Canadian	2
Icelandic Canadian	1
Jewish Canadian	1
Greek	1
Dutch	<u>1</u>
Total	10

Handwritten notes:
W. J. ...
...
...

Appendix D

TABLE 4 - RELIGIOUS AFFILIATIONS

Religion	Number of Families
Roman Catholic	3
Protestant	5
Jewish	1
No Religion	<u>1</u>
Total	10

Appendix E

INTERVIEW GUIDE

1. Can you describe your family to me so that we can talk about your (Probes: ages, children, etcetera).
Sketch Family Tree
2. Could you tell me some of the background about the illness and care of X? (Probes: the beginning, the diagnosis, when you found out about X's condition and how)
3. Now I would like to ask you about the care of X? Your (husband/wife) died at (home/hospital) and (his/her) care took place mainly at (home/ hospital)? Could you tell me what types of decisions had to be made related to the care of X? (Probes: place of care, pain management, treatments, chemotherapy, choice of doctors or health care providers).
4. Who made most of the decisions related to the care of X? (Probes: doctor, family, patient, nurse, combinations of people)
5. Were you involved in the decisions about the care of X?
6. How did you feel about being involved in the decisions about the care of X?

7. Would you have preferred a different type of involvement in the decisions related to the care of X? In what way?
8. Would you say that the way you were involved in the decisions related to the care of X is the way you would have preferred it to be?
9. Do you feel that the fact that your actual involvement was (close to/ different than) the type of involvement you would have preferred affected you in some way?
10. Is it still affecting you in some way? How?
11. Did the involvement in the decisions about the care of X affect the family in any way? How?
12. Have you noticed any changes in your own health during or after this experience?

Appendix F
CONSENT FORM

I, _____, agree to participate in a study entitled "Family Decision Making in Terminal Care." It studies families' preferences and involvement in care decisions. It is conducted by Linda Kristjanson, R.N., Master's student at the School of Nursing, under the direction of Professor Lesley Degner, Associate Professor, School of Nursing, University of Manitoba. My participation will involve approximately one, one-hour interview. My participation is voluntary, and I realize that the researcher and her advisors - Professor L. Degner, Professor P. Farrell, and Professor E. Adaskin, University of Manitoba. The information I provide will be strictly confidential, because no identification will be associated with the information I provide.

Signature

Date

REFERENCES

- Archer, Sarah E. & Fleshman, R.P. Community Health Nursing. second edition, North Scituate, Massachusetts: Dusbury Press, 1979.
- Baldi, de Mandilovitch, Martha A. Informal power elites: the decision making process. Revista de Estudios Sociales, 1974, 40, (11):85-98.
- Bandman, Elsie L. & Bandman, Bertram. The nurse's role in protecting the patient's right to live or die. Advanced Nursing, 1979, 1, (3):21-35.
- Barder, Lea. The silent message-communication in a family with a dying patient. Journal of Marriage and Family Counselling, 1977, 3, (3):23-28.
- Barton, David. Dying and Death. Baltimore: Williams and Wilkes Company, 1977.
- Bates, Erica M. Decision making in critical illness. The Australian and New England Journal of Sociology, 1979, 15, (3):45-54.
- Benoliel, J.Q. The concept of care for a child with leukemia. Nursing Forum, 1972, 11, 194-204.
- Idem. The changing social context for life and death decisions. Essence, 1978,(2):5-10.
- Bierstedt, Robert. The Social Order. New York: McGraw-Hill Book Co., 1963.
- Bracht, N.F. The social nature of chronic disease and disability. Social Work and Health Care, 1979, 5:129-144.
- Bradley, Patricia Hayes. Power, status and upward communication in small decision making groups. Communication Monographs, 1978, 45, (1):33-45.
- * Breu, C. Helping the spouses of critically ill patients. American Journal of Nursing, 1978, 78:50-53.
- Brimigion, J. Living with dying. Nursing'78, 1978, 8:76-79.

- Bruhn, J., Cordova, D., Williams, J., & Fuentes, R. The wellness process. Journal of Community Health, 1977, 2, (3):209-221.
- Buchanan, Allen. Medical paternalism. Philosophy and Public Affairs, 1978, 7, (4):370-390.
- Bursten, B. Family dynamics, the sick role, and medical hospital admissions. Family Process, 1965, 4:206-216.
- Byrne, M. & Thompson, L. Key Concepts for the study and practice of nursing. Saint Louis: The C.V. Mosby Company, 1972.
- Callahan, Eileen M. The "sick role" in chronic illness: some reactions. Journal of Chronic Diseases, 1966, 19:883-897.
- Cancer Care Incorporation of the National Cancer Foundation. Catastrophic Illness: Impact on Families, Proceeding of the Symposium, 1967.
- Carlson, C.E. Symposium on rehabilitation nursing, psychosocial aspects of neurologic disability. Nursing Clinics of North America, 1980, 15:309-20.
- Carper, Barbara A. The ethics of caring. Advances in Nursing Science, 1979, 1, (3):11-19.
- Cassileth, B.R., Zupkis, R.V., Sutton-Smith, K., & March, V. Information and participation preferences among cancer patients. Annals of Internal Medicine, 1980, 92:832-836.
- Clayton, P., Desmarais, L., & Winodur, G. A study of normal bereavement. American Journal of Psychiatry, 1968, 125:168.
- Coe, Rodney. Sociology of Medicine, Toronto: McGraw-Hill Book Company, 1970.
- Cotroneo, Margaret & Krasner, Barbara R. A study of abortion and problems in decision making. Journal of Marriage and Family Counselling, 1977, 3, (1):69-76.
- Curtin, Leah L. The Nurse as Advocate: A Philosophical Foundation for Nursing. Advances in Nursing Science, 1979, 1, (3):1-11.
- Crane, D. Decisions to treat critically ill patients: a comparison of social versus medical considerations. Milbank Memorial Fund Quarterly/Health and Society, 1975, 53:1-33.

- Darling, R.B. Parents, physicians and spina bifida. Hastings Center Report, 1977, 7:10-14.
- * Degner, Lesley F. The relationship between some beliefs held by physicians and their life-prolonging decisions. Omega, 1974, 5:223-232.
- Degner, Lesley F., Beaton, Janet I. and, Glass, Helen P. Life Death Decision Making In Health Care: A Descriptive Theory, Winnipeg, University of Manitoba, 1981.
- Degrange, B.E. Preparing for the death of a spouse: Its effects of adjustment in widowhood, (Doctoral dissertation, Temple University, 1981). Dissertation Abstracts International, 1982, 42, 2982B. (University Microfilms No. 8124559).
- Dewi Rees, W. Bereavement and illness, in Schoenberg, B., Carr, A., Peretz, D., & Dutscher, A. (eds.) Psychosocial Aspects of Terminal Care, New York: Columbia University Press, 1972, p. 210-220.
- Diers, Donna. Research in Nursing Practice. Toronto: J.B. Lippincott Company, 1978.
- Doane, J.A. Family interaction and communication deviance in disturbed and normal families: a review of research. Family Process, 1978, 17:356-376.
- Donabedian, A. Aspects of Medical Care Administration. Boston University Press, 1973.
- Donnelly, G.F., Mengel, A., & Sutterly, D.C. The Nursing System. Toronto: John Wiley and Sons, 1980.
- Donovan, M. & Pierce, S.G. Cancer Care Nursing, New York: Appleton-Century-Crofts, 1976.
- Dunbar, H.P. Emotions and Bodily Changes, fourth edition, New York: Columbia University Press, 1954.
- Engel, George. Grief and grieving. American Journal of Nursing, 1964, 64:94-98.
- Erikson, Milton in Haley, Jay. Uncommon Therapy: The Psychiatric Techniques of Milton Erikson, New York: W.W. Norton Company, 1973.
- Epstein, Nathan B., Bishop, Duane S., & Levin, Sol. The McMaster model of family functioning. Journal of Marriage and Family Counselling, 1978, 4:19-31.

- Flaherty, M. Josephine. The nurse-physician relationship, found in Curtin, Leah & Flaherty, M.J. Nursing Ethics. Maryland: Robert J. Brady Company, 1982.
- Frederickson, Charles G. Life stress and marital conflict: a pilot study. Journal of Marriage and Family Counselling. 1977, 3:41-47.
- Freidson, Eliot. Patients' Views of Medical Practice. New York: Russell Sage Foundation, 1961.
- Garfield, Charles A. Psychosocial Care of the Dying Patient. Toronto: The McGraw-Hill Book Company, 1978.
- Glaser, Barney G. & Strauss, Anselm. Time For Dying. Chicago: Aldine Publishing Company, 1965.
- Idem. Awareness of Dying. Chicago: Aldine Publishing Company, 1968.
- Glick, I., Weiss, R., & Parkes, C. The First Year of Bereavement. New York: John Wiley and Sons, 1974.
- Gottheil, Edward, McGurn, Wealtha C., & Pollak, O. Truth and/or hope for the dying patient. Nursing Digest, 1971, 4:12-14.
- Griffin, J.J. Family decision - a crucial factor in terminating life. American Journal of Nursing, 1975, 75, (5):794-796.
- Grolnick, Lawrence. A family perspective of psychosomatic factors in illness: a review of the literature. Family Process, 1972, 11:457-486.
- *Gyulay, Jo-Eileen, The forgotten grievers. American Journal of Nursing, 1975, 75, (9):1476-1479.
- Haley, Jay. Uncommon Therapy: The Psychiatric Techniques of Milton Erickson, New York: W.W. Norton Company, 1973.
- *Henteleff, P.D. Treatment decisions in the care of the dying. Essence, 1978, 2:15-17.
- Herman, M. A critique of psychosomatics, taken from Weakland, J.H. Family Somatics - A Neglected Edge. Family Process, 1977, 16, (3):263-272.
- Henker, F. Physical illness in disturbed marriages. Medical Times, 1964, 92:206-208.
- Jackson, E. Understanding Grief. New York: Abington Press, 1967.

- Johnson, Dorothy. Powerlessness: a significant determinant in patient behavior. Journal of Nursing Education. 1967, 6, (2):39-44.
- Kastenbaum, Robert J. Death, Society and Human Experience. Saint Louis: The C.V. Mosby Company, 1977.
- Kowalski, G.S. Decision, action, and temporal interdependence. International Journal of Contemporary Sociology, 1977, 14, (3-4):237-248.
- Krause, M.V. & Mahan, L.K. Food, Nutrition, and Diet Therapy. Toronto: W.B. Saunders Company, 1979.
- Krebs, H. Citric acid cycle: a chemical reaction for life. Nursing Mirror, 1979, 149:30-32.
- Kreiger, D. Therapeutic touch, searching for evidence of psychological change. Nursing Mirror, 1979, 79:660-662.
- Kreitman, N. The patient's spouse. British Journal of Psychiatry, 1964, 110:159.
- Kubler-Ross, Elizabeth. On Death and Dying. New York: Macmillan Publishing Company, Inc., 1969.
- Kutscher, Austin. Anticipatory grief, death, and bereavement: a continuum, in Kutscher, A. and Goldberg, M. Caring for the Dying Patient and his Family. New York: Health Sciences Publishing Corporation, 1973.
- Langsley, D.G. & Kaplan, D.M. The treatment of families in crisis. New York: Greene and Stratton, 1968.
- Lefebvre, K.A. Cancer patients and their spouses: a study by selfreport (Doctoral dissertation, University of Tennessee), Dissertation Abstracts International, 1978, 38, 4466B. (University Microfilms No. 7802015).
- Lindemann, Erich. Symptomatology and management of acute grief. American Journal of Psychiatry, 1944, 101:141.
- Maddi, Salvatore R. Personality Theories - A Comparative Analysis. Nobleton, Ontario: Irwin-Dorsey Limited, 1968.
- Mailick, M. The impact of severe illness on the individual and family. Social Work and Health Care, 1979, 5:117-128.
- Martocchio, Benita. Living While Dying. Bowie, Maryland: Robert J. Brady Company, Prentice-Hall Company, 1982.
- Meissner, W.W. Family dynamics and psychosomatic processes. Family Process, 1966, 5:142.

- Murray, J.D. Patient participation in determining psychiatric treatment. Nursing Research, 1974, 23, (4):325-333.
- Okun, Morris A. Adult age and cautiousness in decisions. Human Development, 1976, 19:220-223.
- Otto, Herbert. Family strengths in the treatment process: a research study. Canada's Mental Health, 1966, 14:1-6.
- Palliative Care Program, St. Boniface General Hospital, Winnipeg, Manitoba, 1982.
- Parad, H.J. and Caplan, G. A framework for studying families in crisis, in H.J. Parad (ed.) Crisis Intervention: Selected Readings. New York: Family Services Association of America, 1965.
- Parkes, C.M. Bereavement. New York: International Universities Press, Inc., 1972.
- Polit, D. & Hungler, B. Nursing research: principles and methods. Toronto: J.B. Lippincott Company, 1978.
- Reader, G.G. Highlights From The Round Table. Catastrophic Illness: Impact on Families, Cancer Care Inc. of the National Cancer Foundation, 1967.
- Richardson, H.B. Patients Have Families. New York: Commonwealth Fund, 1948.
- Rioch, D. The psychopathology of death, in A. Simon (ed.), The Physiology of Emotions. Thomas Springfield Illinois, 1961.
- Schaefer, J. The interrelatedness of decision making and the nursing process. American Journal of Nursing, 1974, 74, (10):1825-1855.
- School of Nursing, University of Manitoba, "Health as Energy Flow," May, 1979.
- Schmale, A. Relationship of separation and depression in disease. Report on hospitalized medical population. Psychosomatic Medicine, 1958, 20:259.
- Schulz, David. The Changing Family. Englewood Cliffs, New Jersey: Prentice-Hall Inc., 1972.
- Selye, Hans. The stress of life. New York: The McGraw-Hill Book Company, 1956.
- Shands, H.C. Semiotic Approaches to Psychiatry. Mouton: The Hague, 1970.

- Shapiro, D., Stoyva, J. Kamiyq, J., Barber, T.X., Miller, N., & Schwartz, G.E. Biofeedback and 1979/80 Behavioral Medicine. New York: Aldine Publishing Company, 1981.
- Shubin, Seymour. Cancer widows. Nursing'78, 1978, 8, (4):56-60.
- Sorenson, J.R. Biomedical innovation, uncertainty, and doctor-patient interaction. Journal of Health and Social Behavior, 1974, 15:366-374.
- Stotland, E. The Psychology of Hope. San Francisco: Jossey-Bass, Inc. Publishers, 1969.
- Sudnow, D. Passing On: The Social Organization of Dying. Englewood Cliffs: Prentice-Hall, Inc., 1967.
- Vertinsky, I.B. Thompson, W.Q., & Uyeno, D. Measuring consumer desire for participation in clinical decision making. Health Services Research, 1974, 9:121-134.
- Volkan, V. Typical findings in pathological grief. Psychiatric Quarterly, 1970, 44:231-250.
- Wallace, J.M. Living with stress. Nursing Times, 1978, 74:457-458.
- Walton, D.N. & Fleming, W.H. Responsibility for discontinuation of treatment. Essence, 1980, 4, (2):57-61.
- Weakland, John H. Family somatics - a neglected edge. Family Process, 1977, 16, (3):263-272.
- Weightman, G. Death and the doctors. New Society, 1977, 44, (774):222-224.
- Weisman, A.D. On Dying and Denying. New York: Behavioral Publications, Inc., 1972.
- Idem. Coping with Cancer. Toronto: The McGraw-Hill Book Company, 1979.
- Wickramasekera, I. Biofeedback, Behavior Therapy, and Hypnosis. Chicago: Nelson-Hall, 1976.
- Williamson, Y.M. (ed.) Research Methodology and Its Application to Nursing. Toronto: John Wiley and Sons, 1981.