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Communication patterns of marital dyads experiencing the life-threatening crisis of cancer

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The University of Montana

COMMUNICATION PATTERNS OF MARITAL DYADS

EXPERIENCING THE LIFE-THREATENING CRISIS OF CANCER

By

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DEDICATION

This project is dedicated to all the patients
and families who let me enter into their lives
and share in their beautiful gifts of love,
courage, and insight.

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To my family and friends who have supported me and pushed me to continue, thank you so very much.

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Rarely is the drama of dying played by a single
actor. Usually some supporting cast is involved
and, as a result, the drama partakes of the compli-
cations (and shortcomings) of all human interaction,
including such reactions and emotions as withdrawal,
fear, disgust, shame, guilt and ambivalence. Inter-
actions between a dying person and his survivors-to-
be--loved ones, doctors, nurses and others--are
rather complicated because parties on both sides are
participating in an unusual and extraordinarily
stressful situation.

(Shneidman, 1976, p. 276)

Chapter 1

PURPOSE AND RATIONALE

Three years ago the death of a good friend personally touched my life. As I became physically and emotionally involved in the dying process of this woman, I was able to observe how her approaching death was affecting the family system in which she functioned. Outbursts of anger, time spent away from home, hostile glances, and tearful apologies were just some of the behaviors that seemed to characterize the children's communication. The marital dyadic communication behavior appeared to me to be even more complex because my friend could and would talk very openly about her death, her funeral and the tapes she was making for her family to listen to after she had died, whereas, her husband was usually withdrawn, contributing to the conversation only when the topic was something other than his wife's condition. His only outburst of anger, that I observed, came when she asked him to help her plan her funeral; he would have nothing to do with it.

I, myself, remember feeling uncomfortable with my friend's openness about her death. Now I realize that my discomfort was probably due to the fact that this was the first time anyone had shared their

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dying process with me, and the experience was making me question how
I felt about my own death, which was a new thought and fear (Kubler-Ross,
1969).

My friend's family was and is what I would describe as a sensitive,
caring family who were able to fulfill her wish of wanting to die at
home. When she finally did die, my friend was not alone, nor in pain,
and I believe she was completely at peace with herself and her God.
The same was not true for her survivors.

Bowen (in Guerin, 1976, p. 339) describes the concept of the
"emotional shockwave," which he defines as "a network of 'after shocks'
following serious life events that can occur anywhere in the extended
family system in the months and years following serious emotional
events in a family." This definition, I believe, best describes
what happened to my friend's family after her death.

In the two years following the family's wife, mother, and daughter's
death, they have experienced all types of physical illness. Her
father had a serious heart attack soon after the funeral, and her
mother was hospitalized for chest pains and exhaustion. My friend's
two daughters have been in and out of the hospital with illnesses
ranging from flu and bronchitis to ulcers and colitis. Their father
has had several surgeries for recurring kidney stones.

Emotionally, the family members seemed, at first, to be living
separate lives after the funeral, with all going their own direction.
Drug addiction and failing grades characterized the lives of the two
boys going to college, whereas, the two daughters overwhelmed themselves

with schoolwork and activites. The father took an extended vacation, by himself, soon after his wife's death, and when he returned home, he threw himself into his work. He did have time to date infrequently, which the two daughters seemed to resent, as they related their feelings to me. Because the oldest daughter assumed her mother's role of keeping the home clean, the laundry done, and the meals cooked, she and her younger sister were constantly arguing, with much resentment and bitterness on both sides. Since new roles have yet to be defined for the two, this conflict has yet to be resolved.

Appearances would indicate that this family system is getting by, but the changes the various members have experienced and are experiencing make me question whether the family unit has recovered from the blow inflicted upon it. Then, there are times when I wonder if this family unit will ever completely recover.

I have described this case history in order to show how and why I developed such a strong interest in the field of death and dying, particularly in the area of communication within a family system which is facing the death of one of its members. To further understand the dying process and its ramifications for the social and familial systems in which a person interacts, I started reviewing the literature in the area of death and dying, where I found a vast amount of literature on the topic in general, but only a minimal amount of research concerning communication and the dying process, none of which I found in communication journals, but in sociological/psychological publications. At the same time, I also started working with cancer patients and their families.

My two-year involvement to date with patients and families began with an internship at one of the hospitals in the town where I was doing my graduate coursework in Interpersonal Communication. Under the auspicies of my communication department and with the cooperation of the hospital educational department, I was allowed, as well as encouraged, to study the hospital in general, and the oncology ward, in particular, from three different levels: organizational, social, and functional.

While at the hospital, I was able to interview all levels of personnel: administrators, doctors, nurses, pastoral care members, secretaries, and the housekeeping and kitchen staff. Not being limited to working entirely on the oncology ward allowed me to explore the hospital and to observe as well as participate in hospital life, while always keeping informal notes on all my observations, conversations, and experiences. I would then, at the end of the day, transcribe my notes into a formal journal to be read and discussed by my adviser and me.

Another project I performed while at the hospital was to give the oncological nurses a self-assessment questionnaire about death and dying and terminal care. My reporting of the results at a nurses' meeting precipitated what I would describe as a group therapy session, with the nurses talking in great depth and with much emotion about their thoughts, fears and frustrations in working in a stressful job where there "are few rewards and a lot of hard work." My nursing supervisor and I both listened intently and later expressed similar feelings of surprise at the honesty and length of responses, which indicated to me the need

that medical professionals have for therapeutic outlets when they are working in the area of terminal care.

My internship gave me rich experiences and opportunities to observe and participate in hospital life, while also providing me with enough information and insight to understand the problems, tactics, and strategies used in terminal care. I came away from my internship understanding, on the one hand, that a hospital is an organized, ongoing, political business which, because of its structure and size, cannot possibly provide the intense personal care that patients and families so desperately need. But, I also finished my internship feeling angry and frustrated that such an institution, built on the foundation of caregiving, was not providing adequate psychosocial attention that is such an important aspect of patient care. The more I work with cancer patients and their families, the more I realize that this ongoing conflict of patient versus hospital may never be resolved completely.

After my internship, my husband and I moved to a new town, where I approached a local hospital about doing my thesis research through them. Because I had had no in-depth experience of working with terminally ill patients or their families, the hospital's pastoral care team recommended that I work as a volunteer in the hospital's oncological outpatient clinic, where cancer patients received chemotherapy and radiation treatments. As it has turned out, what was supposed to have been a "brief, initial exposure" to cancer patients developed into a two-year commitment which I hope will continue for a long time.

In my role as a volunteer, I have been able to visit with patients

of all ages and with all types of cancer. While the patients are taking their treatment, I also have been able to observe, informally interview and/or simply listen to the families and friends of these patients, while keeping mental notes about my experiences, which I later write down in a journal. My personal contacts with many of the patients and families have developed into friendships which have remained strong and intact through the dying and bereavement processes. These friendships have also given me first-hand experience in working with families dealing with change or loss. My experiences at the outpatient clinic also motivated me to join the hospital's hospice team, which I did during my second year of volunteering.

The hospice team had been developed a year before in order to give terminally ill patients and their families complete medical and psychosocial care during the dying and bereavement processes. Consisting of nurses, doctors, social workers, pastoral care members and volunteers, with a psychologist being available for consultation when necessary, the hospice team was and is most active in helping families take care of patients who desire to die at home, although the team does work with terminally ill patients in the hospital.

After a three-month period in which I and ten other volunteers were intensely trained in various areas of communication skills, such as active listening and paraphrasing, and were given in-depth information on the medical, psychological and social aspects of working with the terminally ill, I began working as a hospice team member.

As a hospice volunteer, I have filled many roles, depending on the needs of the family. I perform such tasks as cooking and cleaning

for the family in order to give them some respite from the difficult task of running a home and caring for a patient. I have also worked totally with the patient, bathing, medicating, or simply listening to him or her. A hospice team member tries to continually work in a supportive role, however that role is defined by the patient and family. For myself, I have found the role that I am most often placed in is that of a friend and confidante to the patient and family, experiencing the dying and grieving process right along with them, yet attempting to remain a strong support for them.

My experiences with the hospice team and with my volunteering have given, and continue to give me, rich opportunities to study and work with families faced with crisis and change. My experience of informal interviewing, observing, listening to and counseling of the fifteen hospice patients and families that I have become involved with has reinforced my opinion that the area of communication and the dying process needs to be studied in great depth in order that caregivers of all types, whether ministers, doctors, nurses, social workers, therapists, volunteers, or family members, may better communicate and better help those who are facing their own death or the death of a loved one.

One of the main problems that cancer patients discuss during the communication workshops I conduct, under the auspices of the Cancer Society's "I Can Cope" series, is the problem of not being able to or not being allowed to discuss their true feelings or thoughts. Patients and families facing loss or change can and do face a myriad of problems, most of them, in my opinion, surfacing in the area of communication.

Caregivers need to know how to help family systems function during
and after the dying process of one of their members, particularly by
being made aware of the many communication patterns and problems
that families of crises may experience. My personal need to better
understand and research this area in order to help myself and others
to be better communicators with families in crisis, is reflected in
the research question I have developed for this study.

The purpose of this thesis is to study how communication patterns
in a marital dyad are affected when one of the members of that dyad
has been diagnosed as having a life-threatening illness. I have chosen
the communication patterns of a marital dyad for this study in order to
specify my research as well as to study the effect of possible death,
or at least change, on a husband and wife relationship, which would
ultimately affect their entire family system. For this project, I am
defining communication patterns as sequences or episodes of interaction
in enduring relationships which are highly organized and redundant
(Bochner, 1978, p. 184). These redundant, pervasive patterns come to
define the relationship itself. Some of the ways of communicating
help the husband and wife with their developmental tasks of making
meaning out of a life and a relationship, while looking to change.

Some patterns, through their ritualistic nature, hinder the kind
of communication that would allow the dyad to complete their relational
work together. No one kind of pattern can be labeled functional or
dysfunctional without taking into account the goals of the couple and
the ongoing needs of the family.

I am using the term <u>life-threatening</u> in order to communicate the idea that not all cancer is incurable, and since I will be studying cancer patients, where my interest and experience lie, I prefer to describe them as people facing life-threatening illnesses. Although many of my respondents will die from their disease, some of them may have an excellent chance for remission or recovery.

Finally, although I am looking at communication patterns related to life-threatening illness, I also want to study the general communication characteristics of couples facing loss or change. How do people facing their death or the death of a loved one talk about it with each other or with others? How does a life-threatening illness function within a marriage relationship or within a family system? What are general coping styles of individuals and couples undergoing a crisis such as cancer? What communication difficulties are these couples facing? These are just some of the sub-questions that I will be researching with the married couples whose communication I will be studying through qualitative methodology.

Although the American culture seems to be making a major shift from viewing death as a taboo subject toward slowly integrating death into the mainstream of life, researchers have noted that a high percentage of people still die alone and unable to communicate their innermost thoughts and feelings (Bowen, in Guerin, 1976; Epstein, 1975; Kavanaugh, 1972; Kubler-Ross, 1969, 1974, 1975, 1981). Denial on the part of the family members and/or health care professionals can stop the patient from communicating during his or her dying process (Becker,

1973; Feifel, 1963; Kubler-Ross, 1969). Glaser and Strauss (in Shneidman, 1976) note that patients and families can become caught up in a drama of mutual pretense in which all participants in the drama know the truth, but to avoid problems or emotional scenes, everyone pretends that everything is all right. Kubler-Ross (1981) suggests that patients who are caught up in scenes of mutual pretense or conspiracies of silence, will sometimes talk symbolically about their dying, language which caregivers, if sensitive to this kind of communication, can follow up on and use as a means to communicate with the patient.

While reading about these communication patterns and others, I also have observed them working in the family systems I have informally been researching. I have seen how the dying process can be one of the most powerful forces of change, both healthy and unhealthy, within a family structure (Gutmann, in Feifel, 1977). The dying patient has the power to change people's behavior (Weber, 1974), and to control a family's actions and thoughts not only during his or her last days, but for many years to come. The dying process forcefully assaults even the most well-functioning, healthy family systems. Although some family systems do recover and reestablish themselves, other family units take many years and much therapy to recover. And, then, there are many family systems which are never able to reestablish themselves. As I have mentioned before, the need, the demand to study communication patterns and difficulties in families facing change or loss is overwhelming. It is my intention that this study will be

used as a vehicle to help caregivers become more aware and more skillful in dealing with families or crises and their language of change.

Review of Related Literature on Death and Dying

Historically speaking, the family unit has experienced different cyclical levels of involvement with the management of the dying. In essence, death has moved out of the home and into the institution.

In colonial America, the dying were nursed at home, in the midst of family and with the comfort of familiar surroundings (Elder, in Caughill, 1976). "The death watch was a family watch" (Bowman, in Caughill 1976, p.4). After the death, the family was not only able to bathe, dress and bury the body, but they were also allowed to grieve for the deceased in their own personal way (Elder, in Caughill, 1976).

Today it is estimated that about three quarters of the deaths in the United States occur in institutions, despite the fact that a majority of terminally ill patients express a desire to die at home and in the care of those who are loved and beloved (Lerner, 1970). Although it appears that the most intimate process of dying is likely to be managed by strangers in unfamiliar surroundings (Fulton and Gilbert, 1965), the late sixties and early seventies did produce a new trend of studying and   accepting death as a natural part of life. Kubler-Ross (1969), in particular, was instrumental in bringing an awareness of death to a public that had been described as a "death-denying society" (Becker, 1973; Feifel, 1963; Kubler-Ross, 1967, 1969). Kubler-Ross's qualitative

research of terminally ill patients and their families laid the ground-work for other researchers and caregivers to begin viewing and treating terminally ill patients and their families as human beings, with desires, needs, and fears.

Kubler-Ross's research also gave impetus for other changes in the area of death and dying. Researchers started to analyze family support systems (Breu, 1978; Caughill, 1976; Cohen, 1977; Horowitz, 1975; Noll, 1978; Weakland, 1977), as well as medical settings (Hoggatt, 1979; Moss, 1978; Sudnow, 1967). Educational curriculums began to include death education courses, and death became a popular topic of numerous films and literary works. Movements, such as the National Hospice Organization, were organized to give patients and their families complete medical, social and psychological care. The hospice movement, in particular, engendered the need for patients to fully live until death came (Stoddard, 1978). The hospice philosophy of "A person shall never die alone nor in pain," more than any other philosophy of the time, reflected the nation's changing attitude towards those patients facing life-threatening illnesses (Fred Hutchinson Research Center, 1979).

What were Kubler-Ross's findings which so influenced the course and emphasis in the study of death and dying? From her in-depth work with and interviewing of terminally ill patients over a two and a half year period, Kubler-Ross hypothesized that patients and their families experienced five different and unique stages or phases of dying and bereavement, including denial and isolation, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969).

According to Kubler-Ross, reactions of <u>denial and isolation</u> are exemplified by the type of expression that exclaims, "No, not me, it cannot be true!" These reactions may be a healthy way of dealing with a painful situation, for they act as a buffer, allowing the person to collect him/herself and with time, mobilize less radical defenses. When it dawns on a person, "Oh, yes, it is me; it is not a mistake!", <u>denial and isolation</u> are replaced by feelings of <u>anger</u>, rage, envy or resentment. During this stage, <u>anger</u> is displaced in all directions and projected onto everyone and everything (Kubler-Ross, 1969, pp. 38-50).

The third stage, <u>bargaining</u>, is less well-known, but helpful though only for a brief period of time. If a patient has been unable to face facts in the first stage and is angry at people and God in the second stage, s/he may try to succeed in getting some sort of agreement which may postpone the inevitable happening. When a mother secretly begs God to let her live only long enough to see her daughter graduate from high school, she is using the <u>bargaining</u> mechanism in an attempt to postpone her death, a function that bargaining serves. Most bargains are made either with God or with the patient him/herself and are usually kept secret (pp. 82-84).

When a person starts to mourn for what is or will be lost, the stage of <u>depression</u> has been reached. Kubler-Ross notes that there are two types of depression that a patient may experience. <u>Reactive depression</u> is a reaction by the patient to the process of losing everything and everyone he/she loves. Loss of job, family, inability

to function, loss of independence and dignity--all may add to her/his sadness and guilt. In preparatory depression the patient begins to occupy him/herself with the things ahead rather than behind. This type of depression is a tool to prepare the patient for the impending loss of life (pp. 85-86).

The last stage Kubler-Ross observed terminally ill patients experiencing was that of acceptance. It is a stage that may be a state of resignation, void of most feelings. The patient has accepted the realization that s/he is going to die and usually has some readiness to die (pp. 112-114).

More than any other single research effort, Kubler-Ross's identified stages engendered the need for patients to be treated as human beings, with needs and control over their lives. Despite this, Kubler-Ross's research came under heavy scrutiny and criticism from some researchers. Bugen (1977), in particular, questioned the very basis on which Kubler-Ross built her research findings--the concept of stages.

Bugen developed "a model for prediction and intervention," which was based on five theoretical weaknesses which he felt applied to Kubler-Ross's staging approach, criticisms which Kubler-Ross (1974) addressed in her later research by noting that the stages that patients exhibited were not regimented or orderly, but were cyclical, and, in some cases, simultaneously occurring. His critique consisted of the following weaknesses:

1. The stages are not successive.
2. The stages are not separate entities.
3. It is not necessary to experience every stage.
4. Stages may vary idiosyncratically among patients.
5. Little empirical evidence has been offered to sub-
   stantiate the theory of stages (Bugen, 1977, p. 197).

Bugen, in essence, felt that "the existence of a variety of
emotional states is the essential point and not the need to order
them" (p. 197). Instead of using stages for his model, Bugen used
four different contexts of survivorship:

1. a central relationship in which death was perceived
   to have been preventable;
2. a central relationship in which death was perceived
   to have been unpreventable;
3. a peripheral relationship in which death was considered
   to be preventable;
4. a peripheral relationship in which death was considered
   to be unpreventable (p. 206).

Bugen contended that the grieving period could be predicted
to be mild or tense, and brief or prolonged depending on what
situational description applied to the patient and his/her ultimate
survivors (p. 206). He indicated indirectly through his therapeutic
model of intervention and through his criticism of Kubler-Ross, that
he believed grief to be a state of existence, not a process, phase
or stage.

Despite the criticism of her staging process, Kubler-Ross's
findings gave impetus to other researchers to develop their own
stages of dying and bereavement. Lifton and Olsen (1974) delineated
the dying/surviving process for survivors into three modes: numbing,
which they equated with shock (p. 117); constriction, which they
described as "a closing in reaction" which will not allow the

survivor to break free from any perspective, pattern or attitude except that which s/he held at the time of the death (p. 145); and, <u>transformation</u>, a process they described as "establishing continuity amid total disruption" (pp. 135-6).

Kavanaugh (1972), on the other hand, hypothesized that the bereavement process consisted of seven phases: <u>shock</u>, <u>disorganization</u>, <u>volatile emotions</u>, <u>guilt</u>, <u>loss and loneliness</u>, <u>relief</u>, and <u>reestablishment</u> (pp. 111-120). Finally, Greenblatt (1978) posited that there were four processual phases of grief: <u>shock</u>, <u>numbness</u>, and <u>denial</u> and <u>disbelief</u>; <u>pining, yearning, and depression</u>; <u>readjustment to the new environment</u>; and <u>identity reconstruction</u> (p. 47).

Although these and many other research studies indicated the need to view and treat patients and families with new respect, sensitivity and caring, problems still remained. Much of the research of the sixties and seventies indicated the extreme desire of dying patients for clearer communications and supportive relations from both the medical staff and their families, but an equal amount of studies showed, and are still showing, that when such care is provided, it is still more the exception than the rule (Duff, 1968; Simmons, 1972; and Sudnow, 1967). Oken (1968) found, in a study of medical professionals, that 88% of the 219 physicians he interviewed preferred not to tell cancer patients of an unfavorable prognosis. Kram and Caldwell (1969) also found that, in general, physicians, more than any of the other professional groups they studied, recommended evasion rather than telling the truth. And, Feifel (1963) noted

that 69% to 90% of doctors, depending on the study, favored not telling their patients about a terminal illness, rather than following the ideal individual decision.

There is also strong evidence that those working with dying patients find talking about death very trying and avoid it all possible cost (Kalish, 1965; Kastenbaum and Aisenberg, 1972). Glaser and Strauss (in Caughill, 1976) described the breakdown of the psychosocial aspects of patient care as "nonaccountability" (p.19), noting that the socioemotional components of care are not accountable in most hospital situations.

In dealing with the breakdown of communication within a family unit, Parsons (1963) observed that talking about death falls within the context of what he terms "privatization," with death still being considered one of those topics which are considered to be private and/or taboo (pp. 6-61). Elder (in Caughill, 1976) noted that unless there is a legitimate reason for inquiry, entering the conversational area of death and dying without invitation can be seen as "a violation of the sacredness of the self" (p. 22). Consequently, communication can become a drama of "mutual pretense" (Glaser and Strauss, in Shneidman, 1976), resulting in avoidance of the subject of death, and avoidance of the patient.

Waechter (1968) documented the practice of mutual pretense in his study of dying children, finding that nurse and doctor contacts lessened both in number and actual time upon hearing or diagnosing a child as terminal. In their study of the emotional impact

of childhood leukemia on patients and families, Binger et al. (1969)

indicated that the children who were loneliest of all were those

who were aware of their diagnosis, but at the same time recognized

that their parents did not wish them to know. As a result, there

was little or no meaningful communication.

Mutual pretense, conspiracies of silence, and denial are just some of

the communication difficulties that patients, families, and caregivers may

experience during a dying trajectory. For the public, the subject of

death and dying is no longer taboo. But, for the patients individually,

there are still the many medical, social, psychological and communicative

problems that patients of the past have faced. The topic of death

has been generalized to fulfill the surface needs of a curious and

fearful society, but the treatment of death and dying needs to be

personalized to fulfill the very special needs of patients and families

in the state of crisis and/or change.

What is really going on in a patient's life in today's hospitals

and homes? How are a patient's social and familial support systems

affecting and being affected by the dying process? What are a

patient's concerns and how is s/he talking about them? How are

medical professionals and all types of caregivers coping with the

dying and deaths of those with whom they are working? These are

just some of the questions that research must help patients,

families, and caregivers to answer in order that the patient will

truly be able to live until s/he has "to say goodbye" (Kubler-Ross,

1978).

The Patient and Family: A Systems Approach

As Taylor (1979) notes, researchers in the qualitative field usually reach the point of being overwhelmed with the amount of data collected. In their search for ways of organizing and assessing the data, these researchers wrestle with a general dilemma of complexity and confusion. Combining this complexity and confusion with a very limited language in which to describe the data results in many of these researchers becoming defensive, argumentative, impatient, or simply bewildered.

Yet, in researching such topics as family structure and power, symbolic or metaphorical language, or communication interaction, a qualitative, inductive methodology is necessary because it provides sophisticated and sensitive tools with which to study people living in their own system or context and using their own language and behavior patterns. So, in order to reframe the dilemma that qualitative researchers face in dealing with the overwhelming amount of information that such methodological tools as interviewing or participant observation produce, Taylor suggests using the theoretical framework of systems theory to "organize the confusion" (p. 479).

Because of the sensitivity of this research project's subject matter, a qualitative methodology was chosen to study married couples facing crises. And, because of the anticipated potentially overwhelming amount of data the project should produce from the interviewing and observational tools it uses, being able to work within the framework of the systems approach is both practically and

personally appealing. A patient's dying process becomes not only his/her crisis, but it also becomes a crisis situation for the marital and familial systems in which s/he functions.

Upon realizing that a family member has a life-threatening illness, the family is launched into a complex series of events which test the coping strategies of even the most well-functioning families. The diagnosis of this life-threatening disease is an assault not only on the individual person, but also on the entire family unit. The disrupted state in which the family finds itself upon realizing that a member of its group has a life-threatening illness (such as cancer) is a reasonable and normal reaction, and, because the family system is a whole whose parts affect and are affected by each other, all family members respond in some way to the presence of a life-threatening illness in their familial system (Greene,1980).

Sociologists, therapeutic clinicians, and health care professionals have not always been concerned with the effect of an illness, whether psychological or physical, upon the family system. The general pre-1950's trend in the analysis of problematic situations was to study and work with the "symptom bearer" or the "identified patient." This "identified patient" perspective still remains a popular, and, sometimes, necessary approach in studying physical and/or emotional illness, yet, there has been a movement among researchers toward viewing and studying not only the identified patient (IP), but also toward study and work with the familial unit

in which that persons functions.

Although, originally, the systems framework was applied to biological and engineering systems, researchers found that many of the same concepts from these biological and engineering systems could be applied to the ongoing, interactional systems of people. The general systems concepts are particularly applicable to the "dynamic, everchanging process of communication" (Stewart, 1973, p. 57), because these concepts promote a dynamic interactional view of the family unit, an approach which will be most beneficial and productive for this study to use.

Systems Theory

According to the General Systems Theory, "the whole is more than the sum of the parts, with the whole consisting of all the parts plus the way the parts operate, relate, and interact with one another" (Lederer, 1981, p. 253). In viewing a family, systems theorists believe that every relationship has this characteristic of "synergy" or "non-summativity" (Wilmot, 1979 , p. 80), with each relational system "consisting of a continuum of behavioral exchanges between the people involved" (Lederer, 1981, p. 254).

Systems Theory also postulates that there is a constant action/ reaction among all living things. In a group of interacting people, such as a family:

> The behavioral pattern of the group (the whole) is different from the various behavioral patterns of the individual group

members. The behavioral pattern of the group is determined
by the way the individuals in the group relate to one
another, plus, the way each relates to the group. A change
in behavior of one person in the group affects the behavior
of every other person in the group as well as the group itself
(Lederer, 1981, p. 255).

In a marriage, systems theory operates in much the same way as

it does in a family. Usually considered a "subsystem" of a family,

a marital dyad, to be understood and accepted as a system, must be

viewed in its totality, not just as "a rigid or static relationship

between two rigid and static individuals" (Lederer, 1981, p. 255).

The interactional system of the married partners must be considered,

the interactional system being described as a process by which two

or more communicants define the nature of their relationship (Watzla-

wick, Beavin and Jackson, 196.7, p. 121). According to the systems

view, it is this ongoing interactional process, the constant relational,

behavioral exchanges between spouses, that makes their marriage a

"system" (Steinglass, 1978).

Key Concepts of Systems Theory

As Steinglass (1978) notes, in systems theory, there is

attention to organization, to the relationship between parts
to concentration on patterned rather than on linear rela-
tionships, and to a consideration of events in the context
in which they are occurring rather than an isolation of events
from their environmental context (p. 304).

Organization

Steinglass observes, that in looking at a family or a marriage as

a system, "attention" is given to the "organization" of the system.

Every system is organized by the consistent nature of the relationship between the members of that system. To understand and identify the organizational properties of the systems approach, the following concepts should be considered.

Wholeness. Systems theorists propose that if a system is broken down into individual component parts, it cannot be adequately explained or fully understood (Steinglass, 1978) because "all members of a system are interrelated" (Wilmot, 1979 , p. 80), and no single element or subgroup of a system can be thought of as acting independently. As Sandholm (1980) notes, in discussing a marital system, "Wholeness is the uniqueness that is the result of the dynamic interaction occurring between two persons" and "to look at one person in the system apart from the other is to get a distorted picture" (p. 6). Instead of viewing the identified patient as separate from the system, a therapeutic approach, using the systems' property of wholeness, would view the entire system as the "IP," with the critical elements and the relationships of the system being studied from a descriptive stance (Steinglass, 1978). By focusing on the interpersonal and relational aspects of the life-threatening illness and its effect upon a marital dyad, this study's systems framework provides a basis for assessing not only the physical changes which an illness such as cancer can precipitate, but also the psychosocial changes, reactions, and interactions that a marital system may experience in incorporating that illness into its functioning patterns.

When Jane discovers that she has breast cancer, her cancer has ramifications not only for her, but also for her husband, Jim, and for their relational system. Jane's reactions and changes affect and are affected by Jim's changes and reactions, and vice versa. In essence, the cancer becomes "their" illness in that both spouses are being affected by it and are, in turn, communicating and interacting about the cancer depending on their relational perceptions and patterns. To view only Jane as the identified patient (except from a medical/physical point of view) would distort the true picture of how the cancer is affecting Jane and Jim's married life together because their marital system as a whole is being affected by the change inflicted upon it.

In looking at marital systems as the "IP," a perspective which this study takes, the systems approach also gives careful consideration to the boundaries marital or familial systems have developed in order to help them function. If the researcher does not understand or is not aware of how these boundaries function within the relational structure, s/he may never come to know how the system itself functions.

Boundaries. "If systems are consistent elements relating in a consistent fashion, then they are also elements bounded by the nature of the relationship between them" (Steinglass, 1978, p. 4). Because a life-threatening illness may affect the "nature of the relationship" between spouses, in researching the communication patterns of marital systems facing loss or change, the boundaries, or rules (implicit or

explicit) the married participants have developed to define who

participates and how they participate in the spouses' relational

system, must be given attention (Minuchin, 1974).

In many living systems, the spatial relationship of the elements

is so highly patterned that a physical boundary can be discerned

(i.e. a cell membrane). Because marital or familial systems have

no such clearcut or identifiable boundaries, systems theorists

describe the boundaries of these systems by their permeability, or

the "relative ease or difficulty outside persons or elements

experience in moving into and outside of the system" (Steinglass,

1978, p. 309). Skynner (1976) postulates on the critical importance

of understanding the concept of permeability in living systems when

he states:

> Failure of the boundary to restrict exchanges across it
> leads to a loss of difference between the living thing
> and its surroundings, of its separate identity; instead,
> there develops an identity of inside and outside, one
> meaning of death. Too impermeable a boundary preventing
> any exchange, brings another form of death, the fixed
> and stained tissue we see beneath the microscope (p. 5).

To further illustrate Skynner's description, a cancer-stricken

spouse and his/her partner may face all types of new "participants"

in their marital system--doctors, nurses, ministers, other patients,

and even researchers. Larger familial or social networks may

become so strongly active in the married couple's relational life

during this time of crisis that the couple may feel their married

identity or spousal definition is being lost in the rush of new

people and elements (including the cancer itself) which are invading

their lives and disintegrating their formerly rigid boundaries.

On the other hand, the couple's relational boundaries may be so impermeable that they will not allow anyone or anything to upset their marital system. But, the price they may have to pay to keep their system impermeable is that of cutting themselves off from reality, from friends and family, or from each other, as can be seen in those patients who live in a continuous denial or fantasy state, or who completely and consistently withdraw into themselves.

Minuchin (1974) further elaborates on marital types of boundaries when he posits that marriages, in order to function properly, must have clear boundaries in order to insure that a husband and wife are clearly enough defined as a separate system to be protected from interference from competing with other subsystems, such as in-laws and children. When boundaries are unclear, there is uncertainty and confusion between partners about role definitions and decision-making power, a situation which may frequently be created, for example, when the breadwinner of the family finds her/himself dying from cancer. His/her partner may take over the job of earning the family or marital income; children may take over home duties and chores formerly assigned to the patient; and, doctors, nurses, or family members may be making decisions about the patient's life and course of treatment without consulting the patient. Because of his or her illness, the power of decision-making has changed, role definitions are unclear or lost, and there is general uncertainty and confusion about what boundaries or rules prevail.

The clarity of boundaries within a family, according to Minuchin, is a useful parameter for the evaluation of family functioning. For the proper functioning of a family, even the boundaries of the subsystems within it must have clear boundaries in order to allow subsystem members to carry out their functions without undue interference, while also being able to remain in contact with other members of the subsystem and the overall family system (p. 54).

Some families "turn upon themselves to develop their own microcosm" (Minuchin, 1974, p. 54), with communication and concern among family members increasing, distance decreasing and boundaries blurring. As a consequence, "the differentiation of the family system diffuses." Other families develop overly-rigid boundaries, with communication across subsystems becoming stifled and the functioning ability of the subsystems impaired. Minuchin describes these two extremes of family boundary types as enmeshed (diffuse) and disengaged (inappropriately rigid). He contends that all families can be conceived of as falling somewhere along a continuum "where poles are the two extremes of diffuse boundaries and overly rigid boundaries," with most families falling "within the wide normal range" (Minuchin, 1974, p. 54).

In a more recent study of marital and family systems, Olson et al. (1979) further researched family systems and boundaries, using a circumplex model of marital and family behavior, a model developed from the conceptual clustering of numerous concepts from the therapeutic and social science fields and empirically tested and

modified through numerous studies.

Olson's model reveals two significant dimensions of family and marital patterns of interaction, which he and his associates label cohesion and adaptability. The researchers define cohesion as "the emotional bonding members have with one another and the degree of individual autonomy a person experiences in the family system" (p. 5). Using Minuchin's labels, Olson describes the extreme of high familial or marital cohesion as enmeshment, a situation where there is over-identification with the family which causes extreme bonding and limited individual autonomy. The researchers label the low extreme of cohesion as disengagement, which is characterized by low bonding and high autonomy. Olson and his associates contend that when the levels of cohesion are balanced, families can better function as well as deal more effectively with situational stress, such as that caused by illness or death.

In their circumplex model, Olson et al. also describe adaptability as "the ability of a marital/family system to change its power structure, role relationships and relationship rules in response to situational and developmental stress" (p. 12). According to the authors, the levels of adaptability can range from chaotic (very high) to rigid (very low), with the most viable family functioning occurring within the middle levels on the continuum, which Olson labels flexible and structured.

Although Olson et al. contend that families and marriages function best when they achieve a balance on the cohesion continuum as well as

the adaptability scale, they do state that it is possible that
"extreme family types can be functional at some time for some
families" (p. 18). For example, marital or family systems may
exhibit characteristics of extreme cohesiveness (enmeshment) as
a result of the threat of the possible loss of one of the system's
members. In order to cope with that approaching death, the
members may draw on their own and each other's strength and
courage, using their own individual or system resources to help
themselves or each other. On the other hand, a family may go
completely outside of itself to reach out for help or comfort
which the system's members simply cannot or will not provide
(disengagement).

How a family or marriage copes with a life-threatening
illness may depend a great deal on the types of boundaries which
the marital or familial system has created in order to keep a
balanced functioning pattern. Whether the boundaries can be
described as cohesive or adaptable, or enmeshed or disentangled,
these boundaries' permeability will be under assault when a life-
threatening or terminal illness enters into the system which they
help to maintain. How these boundaries function, how they change or
adapt, or how they are able to remain the same when the possibility
of death arises in a relationship will be a prime area of research
for this project.

Hierarchies. A third and final principle related to the system's property of organization is that of hierarchy, which Steinglass (1978) describes as the concept of systems being organized with each other according to a series of hierarchical levels "with each system composed of component subsystems, as well as being a part of a larger supra-system" (p. 309). Marriage, according to Steinglass, would therefore be conceptualized as comprising two individual subsystems, husband and wife, and being, in turn, a subsystem of the family system, which is composed of all its subsystems, and which, in turn, is a subsystem of the social and familial system in which it functions, and so on. In a biological or engineering sense, the hierarchical organization of living systems can become quite complex structurally, and the same can be said of "people" systems.

The concept of hierarchy is essential for this project because the marital dyad will be viewed not only as a husband, a wife, and a relationship (two subsystems and the system they comprise), but the married couple will also be viewed from the stance of their being a subsystem of other more complex systems, such as wider family or social systems. Changes within the husband and wife unit will have ramifications for all the other larger systems in which that marital dyad functions, including the hospital or medical system the spouses may find themselves thrown into because of the life-threatening illness they are facing. How the married unit reacts and adapts to the changes it experiences may depend greatly on the reactions and interactions of other members of other systems of which the dyad

is a part, and, how those systems incorporate the marital dyad's
life-threatening illness into their patterns of functioning will
depend a great deal on the marriage participants' actions, reactions,
and interactions, a circular process which this study will be
researching.

Summary. Wholeness, boundaries, and hierarchy, the organiza-
tional properties of systems, are concepts which are basic to any
discussion or description to the systems approach. They are also
essential principles which help build the theoretical framework
which this project will use in viewing its subjects and assessing
their responses. The circular, interactive relationships which
comprise a system cannot nor should not be dissected into separate
parts, but instead should be studied as they function -- as living
units with structure, boundaries and different levels of complexity.

The Concept of Control

The second major tenet which comprises the systems theory approach
relates to the concept of control.

> Control suggests an image of elements (in living systems)
> in constant dynamic interaction, but able to relate meaning-
> fully to each other because of an intricate and delicate
> series of available mechanisms that, first, keep them within
> an acceptable set of limits and, second, permit adaptation to
> occur" (Steinglass, 1978, p. 309).

In a family or marital system, this controlled adaptation and
interdependence can be related to homeostasis, in which the behavior

of every individual within the family is dependent upon the behavior of the other family members (Watzlawick et al., 1968). The family, because of its interrelatedness, tends to establish a "behavior balance of stability and resist any change from their predetermined level of stability" (Steinglass, 1978, p. 312). Systems theorists postulate that there can be many changes that can occur both within and outside of a system that will not change the system's balance, mainly because of the family's conscious or unconscious efforts to keep or reestablish the status quo (homeostasis). A family's homeostatic state of functioning may be arrived at through different patterns of interaction, mechanisms which will be reviewed later in this section, but, whatever the directions taken to maintain this state, the outcome of the various processes is the same, a homeostatic principle which Watzlawick et al. (1967) describes , as equifinality.

Family homeostasis is a term which has been used to describe the functioning of family systems, particularly "healthy families," but, Speer (1970) contends that the attempt to maintain the status quo is more of a characteristic of disturbed families. He submits that stagnation, stillness, and changelessness (what he terms morphostasis) characterize unhealthy or dysfunctional families, whereas his concept of morphogenesis, having opportunities and mechanisms for change, flexibility, and spontaneity, is more descriptive of healthy families (Beavers, in Lewis et al., 1976). Olson et al. (1979) suggest that

a solution to the morphostasis/morphogenesis conflict is that each

way of functioning, viewed as a system's only approach, may be dysfunc-

tional to a family, whereas the most viable family systems are those

that maintain a balance between both morphogenesis and morphostasis.

As Wertheim (1973) states:

> Without some optimal degree of morphostasis, the family
> system could not survive as a cohesive, viable social
> unit. Extreme morphogenesis, tantamount to constant
> change, would preclude building up of even a minimal
> set of common meanings, values, and expectations,
> essential for communication and the survival of an
> intimate, face-to-face group (p.365).

What mechanisms begin working within a family or a marital

dyad which contribute to the self-regulatory process of homeostasis?

Wiener (1962) submits that the notion of servomechanisms, a concept

drawn from cybernetics, is most appropriate in describing the series

of mechanisms whose primary purpose it is to maintain an acceptable

balance of behavior in the family, and central to this maintenance

theory is the concept of the feedback loop, which, according to

Watzlawick, et al., (1967), plays an important part in the dynamic

growth, learning, and maintenance of the family or marital system:

> Families may be viewed as feedback loops since the behavior
> of each person affects and is affected by the behavior of
> each other person. Input into such a system may be counter-
> acted to maintain stability depending on whether the feedback
> mechanisms are positive or negative (p. 31).

According to Steinglass, in a <u>positive</u> <u>feedback</u> <u>loop</u>, "an increase in any component part of the loop will, in turn, increase the next event in the circular sequence" (p. 313), a situation which Maruyama (1963) calls "deviation-amplifying," and which he also describes as being self-destructive because it sets up a "runaway" situation that can eventually drive the system beyond its boundaries to function (Steinglass, 1978, p. 313).

A deviation-amplifying situation may easily develop in the case of a terminally ill patient who is naturally depressed upon hearing that he cannot be cured. Because of his depression and withdrawal, the patient's family and friends try to cheer him up by instilling false hope into the situation and chattering cheerfully about a positive outcome, new doctors, tests, or cures, while also negating or discounting the few feeble attempts the patient makes in trying to discuss his death with them. ("Now, John, don't talk that way. We all know that you're going to get better, so why don't you just believe us?") Because of the combination of cheerfulness and negation, the patient withdraws even further into himself until he is completely out of touch with everyone, and because the patient withdraws, the family withdraws ("We tried our best, but he just won't talk to us!"), until all are avoiding each other and all lines of communication are broken down. The patient's initial deviation from his family's need for homeostasis, his depression and withdrawal, is compounded by his family's need to disregard and diminish that deviation, a situation which Watzlawick (1974) would describe as "When the solution becomes a problem."

The negative feedback loop, in contrast, attempts to maintain a
balance between the deviations of different events within the loops.
For instance, in a marital dyad a situation might exist in which one
of the spouses is dying. To cope with this crisis state and to main-
tain the pre-dying homeostatic state, both spouses either knowingly or
unknowingly do not address, discuss, or admit that the patient is
going to die, while also keeping daily routines and marital roles
fixed and inflexible. For example, even though the wife appears to
be in the final stages of her lung cancer, with weakness and physical
deterioration taking place, she still handles as many of the family
or marital chores as possible, such as cooking the family meals,
helping the children get ready for school, or consistently performing
her outside job in order to continue her financial contribution to the
family's livelihood. Through all of these activities, she refuses to
broach the subject of dying, which, on the surface, makes it easier
for her friends and family to maintain their normal interactions with
her. Despite her terminal state and because of her need for inde-
pendence and control, this woman acts out her dying process within
the normal or homeostatic patterns of her family's system. Her behavior
indicates to family and friends that this is how she has chosen to
deal with her impending death. And, either by mutual choice or
because of the resulting "safety" and ease of the subject matter of
their interactions when they deal with her, her family and spouse
react in much the same way.

Because of all members' actions and reactions during the dying
process, the pre-dying homeostatis state is maintained, at least until

the death of the patient. In this case study, the patient's need for "normalcy" in order to cope with her dying supersedes any need for honesty or openness that other members of her familial or marital systems may have. And, to achieve this "normalcy" or homeostatic state, the system's individuals either consciously or unconsciously used the negative feedback type of communication to achieve their goal.

Summary. In working with and/or studying cancer patients and their marital or familial systems, the systems concept of control is particularly important. Becoming aware of the need that many couples and families have for leading a life that shows normalcy, even though their lives are being turned upside down because of the crisis they are facing, will help the researcher or caregiver to better understand how a system in crisis copes with the threat of loss or change. And, understanding the subtle mechanisms that work within a system in order to achieve or maintain homeostasis is important and essential for comprehending how a whole system is structured and how it functions.

Many families, on the other hand, do tend toward letting a change, such as life-threatening illness, restructure and redefine their lives, their communication interactions, and their entire living systems. This ongoing process that occurs in some families is also essential for researchers and caregivers to understand. But, research in the field of death and dying consistently shows that incorporating the possible or impending death or dying process into the family/marital structure of functioning, while still trying to maintain some level of homeostasis, is still a prevalent way that people experience,

endure, and cope with such a crisis. It is when that control is lost that many patients feel their battle for life and independence is lost.

The Concept of Energy

A final concept which is essential to any discussion of systems theory is the principle of energy. In all living systems, energy can be freely transported into and out of the system, a process which characterizes these systems as being "open" (Steinglass, 1978, p. 315). The pattern of living systems is based on their organization and available energy in the system, a complex term with a biological basis known as entropy. In a closed system, where no energy is coming from the outside, everything within the system tends to disintegrate and disorganize, but in an open system, life and growth are possible because of negative entropy, or negentropy, "the utilization of energy to develop structure and fight the inexorable downhill pull found in any closed system" (Beavers, in Lewis, et al., 1976, p. 47).

Although entropic and negentropic are terms used in the biological realm of science, social scientists have come to use these terms to describe various types of functioning patterns of familial or marital systems, descriptions and categorizations that will be extremely useful in building a framework for this qualitative research. Familial and marital systems have the same characteristics as those living systems described by biological scientists. All have some type of structural pattern, and most tend to be complex in that structure (even one-celled systems can be described as being complex because of the various functions their structures serve). In families and marriages, as in all living systems, the complexity of the structure of patterning can

be conceptualized as moving on a continuum of organization "from chaos through rigidity, with some differentiation of parts, toward greater flexibility with further evolution of coherent structure" (Beavers, in Lewis, et.al.1976, p.48). This description of the characteristics of open systems as they increase in complexity, or the degree of negentropy, corresponds well with the descriptions of functioning patterns of family and marital systems.

Recent research has produced various typologies which provide a comprehensive and realistic picture of the complexity of marital or familial systems. Many of the today's researchers describe marriages and families as open or closed systems, with additional, more specific descriptions which they apply from their own typological schemes. Olson et al.(1979) give a general description of a family or marriage system that is open, in contrast with one that is closed, as that system where the members have the ability and opportunity to "experience and balance the extremes of being independent from and connected to their families. Individual family members have freedom to be more alone or connected to each other as they wish. However, they seldom remain at either extreme for long periods of time"(p. 18).

Other researchers also describe the concepts of open and closed systems. Kantor and Lehr (1975), for example, characterize family systems as being open (adaptable), closed (emphasizing stability), and random (attempting to maintain free exploration), categories of descriptions which closely parallel other researchers, such as Wertheim (1973), who defines his categories of family functioning as open, partly open, and closed.

Lewis et al. (1976), in their lengthy study of twelve healthy

families, used a theoretical framework of family evaluation which one

of their research scientists, Beavers (1976), had developed from his

on-going experience with the literature as well as his therapeutic

evaluation of family functioning patterns. In order to gain a realistic

perspective of healthy families so as to better understand dysfunctional

families, Lewis and his associates undertook the project of interviewing

members of families and video taping, observing and rating their family

interactions and communication episodes, using Beavers' theoretical

framework to assess their overwhelming amount of data. Because the

general family descriptions that Beavers describes are useful, appli-

cable, as well as theoretically and practically appealing for this

qualitative project, a descriptive review of Beavers' theoretical

basis for family evaluation follows.

A Theoretical Framework for Family Evaluation

In describing families, Beavers' continuum begins with

a description of a "closed" type of system which he calls disturbed.

According to Beavers:

> The most seriously disturbed or chaotic families are quite
> entropic--timeless, repetitive in interaction, clinging in
> a sticky lump (the amorphous family ego mass), having little
> vital interaction with the outside world and little change in
> the family world. Dreams, fantasies, and a studied unawareness
> function in place of goal-directed, active negotiation (p.49).

In the case of marriage participants or families facing or

personally experiencing the dying process, some marital or familial

systems, faced with the stress of loss or change, may exhibit

communication patterns and behaviors which are suggestive of Beavers'
description of seriously distrubed or closed family systems. In
dealing with a loved one's dying process and all of the physical,
emotional, and psychological changes it can precipitate, the chaotic
family may be seen as reacting to and processing through these changes
as if they were of one mind and one thought, ("We feel. . . "; "All of
us think . . ."; "Our family does not break down in public."). Because
the family system has failed to encourage its members to develop clear
and coherent identity formation, the members' reactions to the impending
death of the patient may appear to be dependent on the family's
acceptable, homeostatic style of coping. And, because severely dis-
turbed families show the lowest degree of individuation (as compared
to Beavers' other descriptive categories of families), "the family
members have the least confidence in their ability to survive change"
(Beavers, 1976, p. 69). As a result, they may use maladaptive defenses,
such as denial and fantasy, as their main coping techniques.

As Kubler-Ross (1969) notes, almost every patient or family who
faces a crisis such as death uses denial and/or fantasy at one time or
another in order to cope with the dying process. But, because the
chaotic family has a deep-seated fear of separation or loss, particu-
larly because of the strong, almost clinging dependence members have
on each other, they may continuously and consistently try to obscure
the reality of the situation by their use of denial or by using
stereotyped, repetitive communication patterns to cope with new
encounters (such as those from medical professionals, friends, and/or
other caregivers) which threaten their very rigid, protective

boundaries ("That doctor doesn't know what he's talking about! John is going to be just fine!"; "Everything will turn out okay if we just stick together."). The disturbed family's continuous dependence on these types of coping mechanisms can also occur not only during the dying process of the patient, but also after his/her death, with post-death functioning of chaotic families being characterized as "change-less," because nothing in the family life or structure changes or adapts to the absence of one of its members. Roles and duties remain the same, the family clings even more to their denial and fantasy, and members tend to withdraw even further into themselves. Their "amorphous family ego mass" continues to have little vital interaction with the outside world, clinging only to each other for their main sources of support and comfort (Beavers, in Lewis, et al., 1976). For these entropic systems, there is no opportunity for learning and growth as there is for midrange families, although for midrange families, the growing process is painful and fear-provoking.

Midrange Families. Family systems which are midway on Beavers' continuum of structure (entropic to negentropic) are described by him as being midrange families. Although midrange families have clear and rigid boundaries, they do allow their members to develop some degree of individuation. The children in these families usually are able to develop a modest "repertoire of interpersonal skills" (Beavers, in Lewis, et al.,1976,p.62), but the price they have to pay for attaining these skills and some degree of autonomy can be seen in their guilt-laden self images and neurotic or behavioral disorders.

Control in the standards of behavior, thoughts and feelings is important to midrange families, and, as Beavers notes, the process of individuation is a struggle for the family members, particularly the children, because within the family structure there is an "eerie sensation of an invisible referee" who controls and watches over the family's activities, according those activities an "acceptable" or "unacceptable" label (Beavers, p. 64).

As in the case of severely disturbed families, midrange families cannot accept or abide the separation or loss of a loved one, particularly a parent from a child or a child from a parent. Instead of grieving for the loss and continuing with life, many family or marital participants in this type of family keep the memories of the loved one "burning bright," recreating those lost or dead members through the utilization of other people outside the primary family system, such as a boy who adopts his teacher for his new mother when his own mother dies. Although midrange families do not depend on denial and fantasy as their main coping techniques, as do severely disturbed families, they do tend to recreate or reassign the roles of the dead or dying person in order to keep those members alive in their memories. For midrange families the experience of dying, as well as living, is a painful process particularly because neither experience can be controlled to any great extent.

Healthy Families. The final descriptive category in Beavers' theoretical framework of family evaluation is that of the healthy family. Beavers characterizes healthy families as having clear, but flexible

structures and boundaries. Showing a high level of negentropicism, healthy families accept and encourage change and growth, with even the smallest children being viewed as essential contributors to that growth and change.

These families' communication interactions are characterized by the free flow and exchange of information and emotion. Negotiating, respect for biological drives, intimacy, open expressions of anger which are responded to, all of these are characteristics which can be found in healthy family systems. And, at the heart of all the skills that healthy family systems exhibit is the ability to accept the separation or loss of a loved one (Beavers, in Lewis, et.al.,1976,p.69).

Because healthy families do not "cling" to each other and because members usually feel confident and competent in themselves and in their unique identities, there is no need for family members to depend on fantasy, denial, or recreation in order to deal with the reality of a dying loved one. Healthy families have the ability to reach outside of their systems for comfort and support during the loss of a family members, while also being able to keep their own roles and structure flexible in order to cope with and adapt to the changes that occur because of the illness and death of the family member. The high level of flexibility and individuation in healthy families also enables them to grieve for and accept the death of a loved one, while at the same time restructuring their lives in order to continue to live, grow, and learn after the death has occurred (Beavers, in Lewis, et al.,1976,p.60).

In discussing Beavers' descriptive categories of family function-ing, particularly as they pertain to this study, there are several

additional concepts which need to be addressed before the discussion of

disturbed, midrange, or healthy family and marital systems and their

functioning patterns can be complete. Like Beavers' theoretical

categories, these concepts also are useful to this study because they,

too, help build a framework around which this research project's quali-

tative methodological tools can best be used. The communica-

tion principles to be discussed will be of assistance in guiding the

assessment of the data from "chaos" to "stability."

Communication Principles and Family Functioning

Labeling. As Papp, et al. (1973) notes, families tend to assign or program

each member of their system into a specific, functional role , and then

to label that member accordingly. Although each member does play a

part in assuming his or her functional role, Papp contends that most

labels are "stultifying" in that they prevent growth, while they also,

in reality, have little to do with the true nature of the person.

In families or marriages experiencing the life-threatening illness

of a parent/spouse, labels can sometimes become created or reassigned

due to the changes the illness causes in the family or marital system.

For the person who is the physical sympton bearer of the illness, former

functional role assignments may become lost because family, friends

and/or medical professionals assign him/her a new label--patient.

The label of patient, for many people, implies that they are suddenly

different, abnormal, dysfunctional, or even childlike (Zartman-Nelson,

1980, 1981). In a short period of time, the disease-stricken person

changes labels and roles from "Sue Jones: mother, wife, teacher" to

"Sue Jones: the breast cancer in room 302," a type of experience which Sontag (1977) describes as a "social death."

Although the _patient_ label can become a negative influence in the lives of many people, for others the inability to fully experience the patient role causes them discomfort and emotional pain. For example, a person experiencing cancer (or any other type of life-threatening illness) may be thrown into a situation where s/he is not able to openly go through the reactionary stages of grieving (Kubler-Ross, 1969) because of his or her family's implicit and/or explicit expectation that the person live up to the label of "strong one," a functionary role they had formerly assigned the individual within the context of their familial system. In this case, the former label does not serve its purpose because the family member has changed roles, due to circumstance, but his/her family system, to maintain their homeostatic pattern, attempt to keep the person boxed into the "strong leader" role instead of allowing him/her to grieve for and experience fully the new role of patient that life has assigned her/him (Zartman-Nelson, 1981).

In both of these cases, labeling is shown to be detrimental to the experiential process of the "label victims" involved. The labels are fulfilling a need on the part of the family system, not on the part of the person labeled.

Collaboration. A family or marital system must collaborate in order to maintain a homeostatic pattern of functioning and conflict management, a communication description which is exemplified by the "mutual pretense" context (Glaser and Strauss, in Shneidman, 1976),

which was mentioned earlier in this chapter. But, the "family dance" can be interrupted by anyone who chooses to change his or her behavior permanently, although such change can be elusive and difficult in family or marital systems.

According to Watzlawick et al. (1974), a system may experience two types or levels of change. In a first order change, the family or marital system can experience a change both from within or outside of the system, but which does not affect the homeostatic patterns of the system's functioning. A second order change, however, is a shift that restructures the system or which allows for a way out of the system.

On first glance, the dying or death of a spouse or family member would appear to be a second order change because the absence of the person restructures roles and living patterns, particularly in healthy families. But, it is questionable, and so worth studying, as to whether death presents a second order change for all types of families, particularly those disturbed or midrange families who, as Beavers describes them, cling to their homeostatic patterns, despite the death or dying crisis, by using denial, fantasy, or substitution.

Triangles. Because of the intense interrelatedness and interdependence in family or marital systems, people tend to form triangles in order to gain power, receive attention, build walls or even break down walls between themselves and others. For example, "when one person feels hurt, angry, disappointed, or frustrated with another family member and cannot settle it with them, he tends to bring someone else into the relationship" (Papp, 1973). Children, friends, acquaintances, even family ghosts

(people who have died or moved away) can knowingly or unknowingly be brought into a triangular situation, and if one person in the configuration should shift, the entire triangle will have to shift because new coalitions are being formed or being destroyed (Papp, 1973). If a husband and wife are using one of their children to "make up" for the emptiness that they are feeling in their relationship (i.e., Little Joey becomes their communication link or their only topic of discussion or agreement), their child could very easily shift his position so that he is in a coalition with one parent, thus changing the power structure and/or intent of the triangle.

Although many types of triangles can serve a supportive role, such as a husband/wife coalition which cares for a terminally ill child, many serve a more detrimental purpose, as was discussed in the preceding paragraph. Satir (1967) describes these as "toxic" triangles because they involve crazy-making behavior, particularly for the person in the low power position. And, when a triangular situation is dysfunctional, someone in that triangle will usually start acting out the symptoms of the unhealthy situation (Satir, 1967).

It is especially important to consider triangulation when studying families and marriages experiencing "toxic" or painful events, such as death, for the dying process can precipitate all types of changes within their system's structure and boundaries. Whether those involved with this changing process form triangles in order to cope with the changes, or whether they form triangles in order to restore homeostatic patterns which the changes affect, attention must be given to the function these

triangles serve in the dying process.

A patient who feels powerless because the family and the medical staff are in a coalition of silence against him/her may feel as if s/he is going crazy. On the other hand, a doctor may experience the power of a patient/family coalition when he tries to direct the patient's course of treatment. Whatever the case description, caregivers, researchers and clinicians alike need to understand who the participants of the various triangles are and how the triangles are functioning for those involved, particularly in order to understand system structure and points of therapeutic intervention.

Summary and Conclusion

Systems theory provides a framework by which families experiencing loss can be viewed, studied and analyzed. The basic concepts which have been reviewed comprise the foundation of which this, as well as other qualitative research projects, can study interactional systems in their own context and environment.

Viewing a person facing death from a systems approach allows and encourages the researcher or caregiver to study the person not as a single individual undergoing a unique, painful, and intimate process, but as an essential part of a relational unit experiencing the crisis. A systems approach also allows for recognizing the need to avoid labeling or pointing out the symptom bearer in a system. Instead, the systems (such as illness or bizarre behavior) function for and within the family structure.

The need to help the family and patient facing crisis or change is evident, and to fulfill that need from a therapeutic interventionist approach, one must first understand the system and how it works. A patient's cancer-related needs can, for the most part, be met physically, but psychosocial needs involving spouse and family must be addressed since the patient's dying is affecting the familial unit, and that familial unit is affecting the patient's dying process. A systems perspective provides the caregivers and researchers with the tools to answer not only the "why," but, more importantly, the "how" of a communication situation, and, with these tools, working within the framework of a systems approach, the needs of the patient and family--psychological, emotional, and physical, will have a better potential of being met.

Using a systems approach for this project also provides the impetus for the researcher to study intriguing questions concerning the dying process. How does the dying process affect a family or marital system's structure of power? Can the element of death itself be considered a triangular participant (a patient/dying process type of coalition versus spouse, family, medical staff)? Can an illness such as cancer be a symptom of a dysfunctional system? How do families and marriages cope with the dying process and what do these coping techniques indicate about their health or lack of health? How do rules and roles change when there is the presence of a life-threatening illness? These are only some of the questions and areas of interest that this research can study because of its systems framework.

Communication and the Dying Process

As Kubler-Ross (1972) notes: "The most meaningful help that we can give any relative is to share his feelings before the event of death and to allow him to work through his feelings, whether they are rational or irrational" (in Shneidman, 1976, p. 302). Although research has shown that society in general is dealing with death and dying, people in particular are still experiencing difficulties in facing and/or communicating about their own deaths or the deaths of loved ones. Further evidence of the onslaught of communication problems that families facing terminal illness may experience can be found in the prevalent coping styles people are using while dying or while facing the deaths of loved ones.

Shady (1978) observed, after reviewing the literature on death and dying, that there seemed to be a general consensus by researchers that the following were the predominent coping styles of people involved with in the dying process: denial, depression, anger, suicide, anxiety and fear reactions, regression, dependency and withdrawal. Shady also noted that although many of these styles serve a useful function to patients and families, the incidence of maladaptive coping techniques,(i.e., suicide, regression, withdrawal) suggests the need for better, more honest and open communication, as well as better psychosocial care for patients and families.

From their in-depth work with terminally ill patients and their families, Bogicevic and Rakie (1978) also observed the need for

better communication, noting that patients frequently want to share their thoughts and feelings about death, but their friends and relatives are unwilling to participate, particularly when there is uncertainty about the outcome of the illness. In discussing the communication barriers that he experienced as a cancer patient, Keeling (1976) relates that he, too, had no one with whom to talk or with whom he could share his feelings. Because of his experience Keeling asserts that no human being should have to undergo the cancer experience alone, but, he also notes that for most victims there is no one to offer help.

Instead of an open and honest communication system with the patient, as Keeling hopes for, many family and staff members may find themselves participating in a drama of "mutual pretense," an awareness context Glaser and Strauss (in Shneidman, 1976) first observed while working with terminally ill patients in a small Catholic hospital. According to Glaser and Strauss, a mutual pretense situation begins to develop when the patient, who has some knowledge of his/her dying, may refer openly to his/her impending death, thereby inviting staff or family members either explicity or implicity, to open up the conversation about his/her terminal state.

> If they seem unwilling, he may decide they do not wish
> to confront openly the fact of his death, and then he may,
> out of tact or genuine empathy for their embarrassment or
> distress, keep his silence. He may misinterpret their
> response, of course, but . . . he probably has correctly
> read their reluctance to refer openly to his impending
> death (p. 283).

Because the family and staff may have decided that talking too openly with the patient about his/her death will cause the patient to "go to pieces," they enter into the mutual pretense context, and in order to keep his/her communication interactions with staff and family members on a "safe" and "easy" level, the patient may also knowingly engage in the mutual deception.

Glaser and Strauss also explain that the actors may easily change parts in the drama of mutual pretense. Family and staff members may give cues to the patient, inviting him or her to openly talk about his/her possible death, but the patient may ignore these cues, due to his/her own state of denial, or in order to protect his/her loved ones from "falling apart."

Although denial, fear, and protection seem to be the most apparent reasons why patients, family and staff members may involve themselves in a communication situation such as a mutual pretense, Baider (1977) contends that there is a more basic reason why a mutual pretense episode is created, a reason which, she notes, cannot be described without first discussing the meaning of communication. To do this, Baider refers to the studies in the ethnology of communication (Gumperez and Hymes, 1964), which conceptualize three parts within the communication process.

The first aspect of communication is designated the act of reference, that is, when a person is faced with a sign or message, he recalls his past experience with it, which produces the meaning

of the sign for him. In the second aspect of communication, the
act of inference, the person asks himself, "What does the sign mean
to the one who gave it?", which Mead (1935) described as "taking the
role of the other" (p. 211). The process of communication is
completed by the act of confirmation. Here the person establishes in
two phases the correctness of his inference: (1) by observing whether
the other does indeed perform the action called for by the inferred
meaning of the given sign; and(2) by objectifying the meaning in
one's own conduct. Without the act of confirmation, the communication
process remains on a minimal level of interaction with essentially
independent participants (Baider,1977, p. 24).

Relating this to the role of being sick and the silent messages
that dying people may communicate to others, Baider contends that
certain acts or signals given by the patient, such as moans, withdrawal
or covert requests for attention, are given different meanings by the
various family and staff members, based on their differing and objec-
tive experiences. An act of inference, however, is impossible in the
case of the dying patient. Accepting the assumption that the receivers
of messages need to retain their needs or defenses for safe interactions,
then the nature of their response to the patient must be seen in their
own terms, rather than in view of the patient's expectations and silent
requests.

> The patient's acts of reference do not evoke in others
> the experience he is trying to convey. Not only is his
> process of dying an experience that is unique and individ-
> ual to him, the patient, but, also in his own ambivalence
> of "Why me?", he sends contradictory messages: anger,

fear, and guilt. The feedback he receives confirms for him many times the impossibility of having a more open, meaningful interaction (Baider, 1974, p. 24).

As a result, both patient (sender) and family or staff (receivers) find themselves involved in a conflict of doubt and uncertainty, and engage in a mutual pretense to show each other that this level of communication is the only normal and possible mode of interaction. Between the patient and family and staff, an implicit and mutual acknowledgement is agreed upon as to what is to be spoken and what one may ask or be asked. "Communication then becomes a meaningless process of exchanged verbal messages with a predictable form and content and a stereotyped mode of the entrance of any new internal of external information" (Baider, 1977, p. 25).

Because of this mutual pretense situation, Baider notes, the patient is mostly compelled to invalidate his/her internal experience. The patient's physical deterioration, anguish, pain, and depression over the possible loss of accepted family and social roles (i.e., breadwinner, parent, spouse, boss, friend) can in no way accord with the external experiences of any other family or staff members, nor is the patient able to reinterpret his/her experience of dying for them. Consequently, the family and staff can only sympathize and interact with the imagined or real memories of the healthy person the patient once was (Baider, 1977).

The linear model of communication (sender to receiver) that Baider

uses in her discussion of the mutual pretense context is a description of communication that was popular with the early studies in the communication field. But, with the-expanding and developing field of systems theory, present day researchers view the process of communication as a much more ongoing, dynamic and transactional process. As Wilmot (1979) notes, "You do not communicate to someone. . . you communicate with another. You do not originate communication; you participate in it" (p. 11). Communication is a process that is transactional, with each participant simultaneously creating and deciphering communication cues, while also affecting and being affected by the other (Wilmot, 1979.). The transactional point of view stresses that to accurately describe communication, communication participants need to be thought of as "together," as influencing and being influenced by each other, instead of being viewed as separate "senders" or "receivers" of messages.

Because she is using a linear model of communication for her study, Baider assumes that communication between the patient and family or staff has broken down because the "receivers" of the message (the family and staff) cannot identify with the patient's unique experience of dying and, therefore, cannot attach any personal meaning to the "cues" the patient is sending them.

In Baider's example of mutual pretense, a systems' perspective would, firstly, view all behavior in the situation as communication, and, secondly, would assume that the patient and staff or family are simultaneously sending and receiving communication cues (verbal and

nonverbal), with the relational interaction of those cues and behaviors constituting the communication pattern or level being used.

In a transactional approach, a mutual pretense context would not be viewed as the end result of a communication barrier between a sender and receiver, but, as Glaser and Strauss note, the pretense deception would be a product of communication participants inter-actionally relating and defining their communication roles and behavior within the context of the dying process. In essence, the mutual pretense is not simply the breakdown of a communication system, but the transactional effort of communication participants to keep communication at a safe and "easy" level of interaction.

In discussing the use of deception and pretense, Erickson and Hyerstay (1975) observe that a great deal of time and effort goes into producing an elaborate deception, such as the situation of a mutual pretense, especially since the deception is performed for "an audience that doesn't really want to be deceived, and which already suspects or knows the grim denouement of the drama" (p. 288). Setting aside the question of whether a patient does or does not want to know and/or communicate about his/her terminal state, Erickson and Hyerstay contend that deception of any type is an attempt to invest a terminal patient with a "fictional future biography" and "to control his/her assessment of cues and events that might lead him/her to suspect (or admit) the truth" (p. 288).

Deception, according to Erickson and Hyerstay, presumes to encompass verbal and nonverbal behavior, and they contend that attempting deception is futile, even with the elaborate systems of evasions, double talk and falsehoods, because all people understand and respond not only to verbal cues, but also to concurrent sets of nonverbal cues, such as facial expression, voice pitch, and eye contact. People receive and respond to these nonverbal cues even though they may not be able to identify or understand what they are responding to, and, unless staff or family members are willing to assume that the patient has forgotten what life-long experience has taught him/her, they must concede that the patient is aware of the deception and is willingly engaging in it (a mutual pretense).

Erickson and Hyerstay also submit that a case can be made that attempts by the staff and family to protect the patient from his/her diagnosis and prognosis, may, in fact, set in motion a set of social interactions that are psychologically destructive to the patient. Carried to the extreme, they contend that a patient can become the victim of a "double bind" type of communication situation (Bateson et al, 1956).

The "double bind hypothesis" was developed by researchers who worked with and observed institutionalized schizophrenics. Briefly defined, the double bind is a situation (1) in which a person is faced with contradictory messages(2) which are not readily visible as such because of concealment or denial or because messages are on

different levels, and (3) in which he can neither escape or notice and effectively comment on the contradictions" (Weakland, in Jackson, 1960, pp. 373-388). The inability to escape is the result of dependence on those giving the contradictory messages, a dependency inherent in childhood or illness.

Bateson et al. (1971) suggest that when a normal person is caught in a double bind, s/he will respond in a defensive manner similar to that of a schizophrenic, but given the double bind as a recurrent theme in a person's experience so that the double bind structure comes to be a habitual expectation, more serious effects may follow, such as the inability to discriminate or judge messages and interpret their meanings. The victim of the double bind experiences helplessness, fear and rage, and may respond with misinterpretations and distortions of reality, inappropriate emotional responsiveness, and loss of empathy for others (Erickson and Hyerstay, 1975, p. 291).

According to Erickson and Hyerstay, a patient who is caught up in a "conspiracy of silence" may have a good chance of being the victim of a double bind situation. Firstly, the patient has been denied information about his/her illness. Secondly, the patient is receiving contradictory messages about her/his condition. Verbally, family and staff are reassuring the patient that "all is well," but non-verbally, the patient is picking up cues (i.e. eye contact, facial expressions, tone of voice) that "all is not well," that something is amiss. Thirdly, no one, including the doctor, will straighten

out the mass of confusing and contradictory messages by openly

confirming or disconfirming the patients suspicion. And, lastly,

the patient can't escape from this double bind situation because

of his/her physical dependence on the hospital and family during

the illness.

In order to get our of the bind, Erickson and Hyerstay note,

the patient is asked to take on an unbelievable task. S/he must, on

her/his own, accept the fact that s/he is dying and take the risk

of expressing the metacommunicative message: "It is obvious to me

you are uncomfortable and evasive around me because I am dying and

you are having difficulty dealing with me as a dying person" (p. 293).

Because the patient has violated the communication pattern which was

essential to maintain the "safeness" and "normality" of the interac-

tions with family and staff, s/he may experience a type of punishment

in the form of anger, withdrawn love, avoidance and abandonment, or

the patient may simply be faced with more concealment and denial. Yet,

such a courageous metacommunicative act may encourage a cathartic

release of emotion and information from the family and staff, so that

the patient can manage to work through his/her crisis, with the possi-

bility of sharing openly and honestly with loved ones during his/her

last days.

No discussion of communication during the dying trajectory can

be made without mentioning four issues which researchers (Feifel,

1955; Hinton, 1967; Saunders, 1959; Weisman and Hackett, 1961; and

Kubler-Ross, 1969) report are crucial in the dying process:

1. Despite what has been told and what withheld, most dying patients know the truth about their illness.

2. Familiarity with the unpleasant facts of terminal illness need not destroy hope and breed despair.

3. Fear of death itself is seldom expressed. It is fear of the dying process that produce distress.

4. Most patients do not ask directly about their prognosis. They do so indirectly (Hackett, 1976, p. 372).

As can be seen, all of these points hinge on communication. They revolve around whether or not to be open and truthful with a patient. Hackett (1976) asserts that because of the new openness and education about death and dying, doctors, including himself, are being more honest with patients. His concern is that both medical professionals and family members communicate the news of a diagnosis and prognosis in such a way so as not to destroy hope. Kubler-Ross (1969, 1974, 1981) and Zorza (1980) both address the issue of "hopeful communication," that is, open and honest interactions which do not instill a false reality about the gravity of the situation, but do not take away all hope of a possible recovery, remission, or, ultimately, a better way of living each day to its fullest (McElvoy, 1979). This communication is the type observed in families and/or hospital situations where the patient is allowed and encouraged to openly work through the various stages of reactions s/he may be experiencing during the dying process (Kubler-Ross, 1969). While working through these stages, hopeful communication also encourages the patient to mobilize his/her physical and emotional defenses in order to fight

the disease and/or to cope with the changes the illness brings.

If the patient has not been allowed to work through the various stages of dying, or, is stuck in one type of reaction, such as denial or depression, Kubler Ross (1969, 1974, 1981) notes that caregivers, if they are sensitive and observant, can understand the symbolic communication that some patients will use, particularly when they are not yet ready, or do not wish to verbalize about their illness. A patient may metaphorically or nonverbally signal what his/her true feelings and perceptions are when s/he cannot or chooses not to talk openly with others. To understand symbolic language, Kubler-Ross notes, it takes time, experience, and patience, and, even then, she observes, "We still make many mistakes, and are often unable to make the right interpretation. But, if I communicate with a patient and the patient responds positively, I presume that I made the right interpretation" (Kubler-Ross, 1969, pp. 50-51). Kubler-Ross also observes that her communication with a patient who is using symbolic language most often takes the form of the symbolic language the patient is using. It is only after she feels the patient is ready to "put it into plain English" that she, too, will use "plain English" in her response. If the patient does not then use the same type of communication in return, Kubler-Ross notes that she, too, will go back to using the same type of symbolic language, in order that the patient will feel completely comfortable and non-threatened in his/her communication interactions with her (Kubler-Ross, 1974).

Examples of symbolic language, according to Kubler-Ross, are nonverbal gestures (i.e. a hand held tighter, which could possibly mean "I'm afraid, "I'm uncomfortable," or "I'm glad you are here."), drawings (i.e. a child drawing a picture of a balloon floating free, which may portray his/her feelings about death being a type of "floating away" or a new type of freedom), and metaphorical language (a man saying to his niece two hours before his death, "It's getting late in the day.") (Zartman-Nelson, 1980, p. 22). Whatever the form symbolic language takes, Kubler-Ross states that it is extremely important to become aware of it as a definite means of communication, particularly with patients who cannot or will not talk about their dying in any other way (Kubler-Ross, 1969, pp. 50-51).

Research in the area of communication and the dying process has been sketchy at best. As can be seen from this review, certain communication patterns, such as deception, double-binding, and symbolic language, have been observed and researched. But because every person is unique, every communication system used during the dying process is unique, and every family's communication patterns are unique to and reflective of that family's rule system and response to change or loss.

How are family members responding to the loss or the impending death of a loved one? How is the family, as a system, affected by the dying process of one of its members? The impact of serious illness and/or death on the family unit will be discussed next.

Reverberations Throughout the Family System

Baider (1977) notes, ". . . the modes of communication within the family reflect the nature of their familial relationships through the verbal and nonverbal communicative processes they use, with external events being translated into internal experience" (p. 24). In a family system, if the external event is the dying or death of one of its members, how does that family system translate that external experience into an internal one, and, how is that internal experience then communicated within the family unit? Although these are questions that many of today's caregivers have pondered, only a few systems researchers have studied them with any great depth.

Krant and Johnston (1978) were two of the first researchers to do in-depth work in the area of terminal illness and its impact on the family system. From their interviews of 126 first-order relatives facing the loss of a loved one, Krant and Johnston were able to assess people's perceptions of their communication during the dying process of family members.

Krant and Johnston's results, taken from a sample which included forty-three spouses, sixty-six children, twelve siblings and five mothers, indicated that when late-stage cancer exists, many close family members do not perceive that they have a communicative link to the medical staff or hospital (p. 213). Close family members also indicated that they frequently learned of a patient's diagnosis through a non-medical source, such as other family members or friends. A majority of those interviewed indicated that they did

not know the name of the attending physician nor did they find him/
her helpful.

As Krant and Johnston note, the issue of a communication
problem between the doctor and patient and/or family is complicated
not only by the physician's questionable communication techniques,
but also by the family members' psychological defenses, which they
use to deal with the level of anxiety about the terminal illness.
According to the researchers, factors such as the family's dependence
on the patient, the degree of emotional involvement with the patient
and the manner in which antecedent crises have been handled were
determiners of the level of anxiety the family members were feeling
(p. 213).

Krant and Johnston also observe that those psychological
defenses that the family might use, such as denial, projection, and
displacement of hostility, may distort family members' perceptions of
their communication both within and outside of their family system.
As a result, family members who are having trouble dealing with and
accepting the terminal state of a patient may well find blame with
a physician or any other type of caregiver who wishes to communicate
any realistic information to them.

Krant and Johnston note in their study that a number of family
members exhibited a position that might be called "middle knowledge"
(Weisman, in Shneidman, 1976), in that they perceived the situation
as being optimistic, believing that the patient is getting better,
while also entertaining the thought that the patient will die (p. 459).

Because of this "middle-knowledge" type of position, as well as

seeing the patient in pain, many family members expressed that they

felt helpless and uncomfortable around the patient (p. 214).

Communication within the family nexus was described by Krant

and Johnston as "limited at best," as witnessed by their observation

that "a quarter of the people sampled felt that others in the family,

including the patient, did not know what was going on" (p. 214).

Patients reported the same information, but from their point of view.

The least shared communication between family members and patients

was in the area of dying or dying-related issues. While 70% of the

family members felt that the patient was dying, only 25% of the

patients interviewed openly acknowledged that they were sick or dying.

Only 22% of the 216 interviewed had ever talked with the patient

about his/her death (p. 214).

Krant and Johnston's study of family members' perceptions of

communication in the terminal stages of cancer produced two other

important and final observations: (1) families and patients did

communicate about disease related issues only when the family member

and the patient were consonant and agreed that they knew what was

happening, and(2) most family members did not exhibit a positive

feeling that the patient should die at home (p. 215). To explain

this last observation, Krant and Johnston submit that the hospital

is frequently asked to bear the responsibility of the patient's dying,

especially when the communication between a family and patient is

poor. When a patient is seen as withdrawing and/or not communicating,

family members are especially prone to wish to have him or her die
in the hospital rather than at home (p.214).

In another study of family communication patterns during the
terminal illness of a family member, Cohen et al. (1977) interviewed
twenty-nine middle-class families who had experienced a terminal
illness and death of one of their members, in this case the parent/
spouse. Using interviews, questionnaires and observations, the
researchers determined that:

1. The pre-death communication patterns of the family did not
significantly affect how a family utilizes external support systems,
such as schools, agencies, friends, clergy, and so forth. There was
a significant correlation between the free flow of information and the
utilization of internal support systems, such as family members or
family structure (i.e. roles, routines).

2. Post-death restabilization showed a significant correlation
with the effective use of external support systems, as well as the
utilization of the free-flow of information. The more family members
were able to communicate with one another, to share information, and
to share in the decision-making, the greater the likelihood of an
effective adjustment during the post-death period. The researchers
assessed "adjustment" by using the data produced from the various
methodological instruments--structured and semi-structured interviews,
questions and observations, and correlating that pool of data, using
a chi square method of analysis.

3. Those families in which the patient who died was the mother were significantly rated lower in communication patterns than those in which the father had died, a finding that could possibly be explained, as Cohen notes, from a sociological perspective, which traditionally describes the adult female as the "expressive" leader and integrator for the family (Cohen et al., 1977, p. 225).

4. Families that were rated as having "open" communication systems were families which were flexible about changing roles during and after the death of the patient. These families put emphasis not only on the patient's illness, but also on how that illness was affecting the future functioning of the family (p. 226).

5. The researchers determined that the more inwardly directed the family (centripetal), the more likely it was to make effective use of external support systems, a finding which strongly supported a position which was completely opposite of what the researchers had hypothesized. Cohen et al. also noted that centripetal families tended to rate significantly better than centrifugal (outwardly directed) families on the effectiveness of post-death restabilization. Although the study did not make any conclusions about these surprising findings, the significant correlation between a centripetal family's use of external support systems, such as friends, neighbors, hospital personnel, and its effectiveness in post-death restabilization would indicate that centripetal families because of their structure, (1)may have more external resources on which to depend during times

of crises, or(2) may not actually have more external support systems (in number) than do centrifugal families, but may make more use out of the ones they come in contact with, an explanation that is based on the finding that no family that was classified as centripetal listed the physician as helpful at the time of death, whereas, half of the families classified as centrifugal responded with "physician" to the open-ended question, "What people were helpful at the time of death?" (Cohen et al., 1977, p. 226).

6. Although 98% of the surviving spouses learned that the patient had cancer at the time of diagnosis, only about 50% of the children under eight learned about the diagnosis during the terminal state, and a few learned after death, findings which support the researchers' general observations that there was a reluctance on the part of the families to discuss the seriousness of the parent's illness with children.

From these findings, researchers hypothesized that for a parent, the task of informing his/her children of his/her impending death is painful. S/he grieves over not being able to complete the task as a parent in rearing the child. Although most patients, when asked why they hadn't informed their child about the gravity of their illness, expressed reasons, such as the fear of breaking down in front of the child or of being unable to deal with a strong show of feelings on the part of the child. Researchers generally felt that the reasons for the communication barriers with the children had more to

do with the complexities of the unfulfilled parent-role and the ensuing guilt and anger, than with fear of an emotional scene.

7, A general conclusion made by the researchers from their study was that even families which they would describe as having open communication systems find it difficult to discuss the nature of illness and impending death of a parent. The findings of the study strongly support the thesis that families experiencing terminal illness and death of a loved one are under a great deal of stress   (Cohen, et al., 1977, pp. 223-228).

As can be seen from the various findings from family studies, an entire family may be in crises because one of its members is dying. Traditionally, the family is viewed as the first line of defense to support one of its members who faces a crisis, but because a terminal illness affects not only the patient, but the familial relationships, the entire integrity of the family system is under assault (Giacquinta, 1977). In studying the communication patterns of patients and families facing death, therapeutically the family and patient must be treated as part of a unit or system because illness has ramifications for all members of the family, with actions, reactions and interactions reflecting the family's internalization of external events. The family's communication patterns are indicative of the family's rule system and definition. If, as Kubler-Ross notes, a person dies as s/he has lived, can one also conclude that as a family copes with life, so it will cope with the death of one of its members? Only much needed research in the area of family communication will determine this.

Communication and the Marital Dyad

Because marital dyads are frequently described as "subsets" of family systems, and are frequently and popularly included and addressed in the family systems/communication literature, Steinglass (1978) notes that there are few, if any, theoretical statements unique to marriage. The review of the research done on couple communication during terminal illness would substantiate Steinglass' statement that there seems to be minimal theoretical work done in the area.

In one of the few studies done on communication within a marital dyad in which one of the members has a terminal illness, Leiber et al.(1976) studied thirty-eight married couples, characterized as having mature and enduring relationships, all of whom had one of the spouses receiving chemotherapy for advanced cancer. Through interviewing patients and spouses and giving them the Beck Depression Inventory and an Affectional Needs and Behavior Scale, the researcher's assessed changes since illness in the couple's desire for affection, (sexual, physical, and verbal) and changes in actual affectional behavior (p. 379).

The results of the study indicated that for the majority of these long-married couples, the stresses of a life-threatening illness did not produce emotional alienation or withdrawal. Moreover, the frequency of their feelings of affection and protectiveness toward each other either remained unchanged, or, if changed was much more

likely to increase than decrease. Each spouse indicated that his/
her primary concern was for the other spouse, and in their verbal
communication "they maintained whatever degree of intimacy they
had prior to the illness, or they talked with each other and found
it easier to discuss personal matters" (p. 386). A majority of the
patients and spouses also simultaneously experienced a decrease in
the desire for sexual intercourse and an increase in the need for
nonsexual physical contact and closeness (p. 386).

The findings of the study also suggested that the desires of
the patient, rather than the spouse, exerted greater control over
the couple's affectional behavior. With women patients acknowledging
the highest degree of affective depression and their husbands acknow-
ledging the lowest, the researchers theorized that the women patients may
have been openly expressing their fears, worries, needs and desires
(the "expressive" leader, as Cohen noted), while their husbands may
have tended to suppress needs of their own that ran counter to those
of their ill wives. Also, because researchers found that male patients
and their wives agreed less than female patients and their husbands
with regard to desires and concerns, they felt the finding may reflect,
at least in part, the greater difficulty in fulfilling traditional
role expectations when it is the male partner who is victim of the
debillitating and life-threatening illness (p.387).

Leiber's and Cohen's findings support the observations that many re-
searchers have made about the variety of changes that patients and spouses

experience with the onslaught of a life-threatening illness. Johnson (1976) is another researcher whose findings can be added to the small but growing numbers of studies which are being done on the marital system facing change or loss.

Johnson's study examined the communication patterns of husbands and wives before, during and after one of the spouses had undergone cancer treatment. She also designed the study to examine how the cancer affected the marital relationship in general.

Using an open-ended interview method only, Johnson designed her interview questions to elicit from her eighteen respondents (nine couples) information pertaining to sexual concerns, body image, self-esteem and patient-health professional communication. Some of the following questions were included in her study:

1. Are you satisfied with your sexual life?

2. Has it changed since the occurrence of the cancer?

3. Do you and your spouse talk about your illness?

4. How has your body changed since treatment started?

5. How is your partner responding to your body changes?
   (Johnson, 1976, p. 187)

These and other questions provided the basic data which showed that persons with cancer who had positive self-images were better able to talk to their spouses about their illness and its physical, psychological and social implications than were persons with a comparatively low self-image. Weisman (1972), in discussing denial and self-esteem,

submits that patients who deny a great deal seem to do so not only to avoid the realization of the possible loss of life and love relationships, but to preserve a high level of self-esteem and to maintain the status quo of the familial system, particularly whenever a life-threatening illness promises to be humiliating, extended or incapacitating (p. 460). Both Johnson's and Weisman's research indicate. that how people feel about themselves may have a strong influence on how, or if they communicate with their spouses and other family members. Leiber's and Johnson's studies strongly suggest that if cancer patients and their spouses are to receive complete psychosocial care, with attention to self-esteem, the sexual concerns of the patient and spouse must be included in the pattern of care.

In the last study to be reviewed in this section on marital communication during terminal illness, Sheehy (1977) researched the rules of dying that married couples developed during the dying trajectory of one of the spouses. In assessing patient and spouse anxiety, Sheehy's in-depth interviewing of cancer patients and their husbands or wives produced the following findings: (1) The central factor for a patient's adjustment to dying was his/her perception of the concurrence with the spouses expectations of the outcome of the disease;(2) Patients have the lowest alienation from the spouse when most of the definitions about one another's feelings and adjustments to the illness are nondisparate; and(3) Role expectations which require "realistic" orientations to impending death or which assign

the patient a privileged dying status, are more alienating and less adjustive than are expectations which treat the situation according to a "pretense," as if there is no fatal illness.

The last finding was based on the responses of a majority of the ten couples interviewed, who expressed opinions about communication which followed a general theme of "life goes more smoothy when we don't talk about it (the illness)." Many respondents related that they did not openly address their spouses' dying, or if they were in the patient's role, they voiced the opinion that "the less said, the better." They did not want to talk about their cancer, nor be reminded that they had it.

Sheehy's observation that "pretense" may be used as a less alienating and more adjustive orientation for married couples facing the loss of a spouse may relate to the needs of some families to keep their homeostatic patterns of functioning, even though they are facing a structural change to their marital and/or familial system-- the death of one of the system's members. The need for "normalcy", which may take the form of pretense, is an overriding goal for some families or marriages, where the free-flow of information or emotion would only be a threat to their homeostatic nature of functioning.

Maddison (1972) termed intrafamily restrained communications as "conspiracies of silence," and other researchers (Glaser and Strauss, in Shneidman, 1976; Erickson and Hyerstay, 1975; Kubler-Ross, 1969) discuss certain communication patterns as pathogenic or destructive

(i.e. deception, double-binding, mutual pretense), denying for family and patient alike an opportunity to work through anxieties, to share remaining pleasures, and to plan realistically for the future. As Olson (1972) notes, among the characteristics that help a family make a good readjustment is direct and consistent communication. Yet, other researchers (Hackett, 1976; Sheehy, 1977; and Cohen et al., 1977) who have studied families and couples in crises hint at the idea that changes of communication patterns which some of these people have used in their intrafamilial and interfamilial systems do not alter the quality of life for patients or family members before death. Perhaps research should not study communication patterns within the family or marital dyad from a "healthy" or "destructive" viewpoint, but from the viewpoint of how the communication interactions are functioning within that familial or marital system. If a couple is using a "mutual pretense" type of communication, how is it functioning for them within their relationship? How does illness function within a family? How do people use symbolic language to communicate what they cannot verbalize? What do the communication patterns of a family or couple reflect about their system? These and many other similar questions need to be addressed fully before the systems approach to the study of communication in families or marriages facing change or loss can be fully understood and therapeutically implemented.

Summary

The language of change reflects how an individual or a marital/
familial system translates an external event into an internal experi-
ence, which can then be communicated to others. The communication of that
experience can take many forms, particularly verbal and nonverbal, and
can occur on several different levels, such as content and relational
levels, but however the communication interaction is occurring, the
participants of that interaction are all involved in a circular,
ongoing, in-process transaction where they are simultaneously sending
communication cues and receiving them while, affecting and being
affected by those cues.

Communication during the dying process involves all of the
characteristics and complexities of communication which occurs in
the living process, except for one added dimension -- the influential
effect of impending loss or change on couples' or families' homeo-
static patterns, routines and roles. The depth of that effect and
how it translates into a marital or familial system's structure and
functioning is an area of crisis communication which needs to be
studied in order to give impetus for helpful and constructive
intervention and/or support for people involved with change or loss.

Chapter 2

METHODOLOGY

The Qualitative Research Process

The purpose of this project is to study the communication process
of marital dyads experiencing a life-threatening illness. In order to
study these couples facing crises, as noted in chapter one, a quali-
tative methodology was chosen because of its approach of studying the
human experience within its natural setting and context, which is both
necessary and desirable when considering the depth and sensitivity of
the topic being researched.

Qualitative methodology first became popular in the American
sociological studies around the turn of the century. It was during
that time that sociologists from the "Chicago School" began to view
the use of such methods as participant observation and/or personal
documents as "the perfect type of sociological material" (Thomas and
Znaniecki, 1927, p.1832) because of the very real picture these methods
conveyed about people interacting with their environment and their
society. Interest in the qualitative area of research lessened in
the 1940's and fifties when researchers' use of other methodological
approaches, such as quantitative analysis, grew, but the 1960's and
seventies saw a reemergence of the use of the qualitative approach,
as social scientists experienced the growing need to implement methodo-
logical techniques which would produce descriptive data that used people's
own written or spoken words, or their own observable behavior as re-
sources (Bogdan and Taylor, 1975).

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Qualitative methodology approaches problems and seeks answers by allowing, as well as necessarily involving the researcher, to some degree, into the lives of his/her subjects. And, as Bogdan and Taylor further discuss, the qualitative methodological tools:

> allow us to know people personally and to see them as they are developing their own definitions of the world. We experience what they experience in their daily struggles with their society. We learn about groups and experiences about which we may know nothing. Finally, qualitative methods enable us to explore concepts whose essence is lost in other approaches. Such concepts as beauty, pain, faith, suffering, frustration, hope and love can be studied as they are defined and experienced by real people in their everyday lives (p.5).

The process of living can be filled with many of the concepts that Bogdan and Taylor describe, but the pivotal point between living and dying, that experience which makes people realize the fragility of life and the vulnerability of the human condition, may either diminish or intensify the "essence" of many of these concepts. To fully understand the process of action/reaction/interaction that occurs when such an experience is faced, the sensitive methodological tools of the qualitative approach, such as interviewing or participant observation, allow and encourage the researcher to enter into the life-threatening experience of her/his subjects and to gather data that is rich in insight and information because it comes from the words and behaviors of the subjects. Although the researcher does not accept the subjects' perspectives as truth, the qualitative experience of sharing the lives of those people helps the researcher to develop an empathy which allows him/her to see the world from

their viewpoint (Bogdan and Taylor, 1975, p.8).

Besides the rich descriptive data that a qualitative methodology can produce from its natural approach, Glaser and Strauss (in Filstead, 1970), contend that this framework has another important and useful purpose. From their in-depth qualitative studies of terminal care, Glaser and Strauss submit that their interviewing and participant observation of terminally ill patients in various hospitals provided them with a foundation upon which to build substantive theory, which they describe as "the formulation of concepts and their interrelation into a set of hypotheses for a given substantive area--such as patient care...based on research in the area" (p.288). An essential area of attention when researching patient care is that of the familial unit as it experiences the life-threatening illness of one of its members. The substantive theory derived from the researcher's qualitative study of the embattled family system can be used not only to describe the life-threatening experience itself, but also to describe the patterns of communication and behavior and how they function for the system undergoing the crisis. This theoretical stance can then precipitate appropriate and constructive therapeutic interventions specifically, and healthy caregiving techniques generally.

Lofland (1971) notes that the "qualitative study of people in situ is a process of discovery" (p.4). When Kubler-Ross (1969, 1974, 1981) entered into the lives of her terminally ill patients, using her qualitative tools of interviewing and participant observation, she "discovered" that patients seemed to have similar types of reactions

when going through the dying process (i.e. denial, anger, bargaining, depression, and acceptance). While her qualitative tools produced for her observed and elicited descriptive data, the qualitative approach also allowed her to view her patients' situation from an inductive point of view. Along with elicited, observable data, Kubler-Ross's questions, hunches and insight, in essence, her intuitive sense, guided her inductively through her research experiences so that she could later systematically formulate and verify the ideas that would form the foundation of her substantive theories (Glaser and Strauss, 1970). But, even with the substantive theories that Kubler-Ross developed from her research, the need for further qualitative studies in the area of death and dying can be seen in the lack of specific communication studies in the field, as was noted in chapter one. However, qualitative research in the area of communication during the living process abounds. Out of this "abundance," the following studies have been chosen for review because they use procedures and techniques that this research project will be implementing.

Research in the area of communication that relies heavily on qualitative techniques includes a study by Borman, Pratt and Putnam (1978) which studied the communication process of a developing organization. Using diaries, tape recordings and analyses by participant and nonparticipant observers, Borman and his associates discovered an emergent proposition while in the field (McCall and Simmons, 1969, p.237); that is, they discovered data during their research process which caused them to refocus their attention from

communication behaviors concerning leadership to the area of sexual power plays and the effect of emerging female leadership on the men in the group (and their subsequent withdrawal or feelings of inadequacy).

As will be noted later in this chapter, taping and tape recording analysis will be essential techniques for this study's research procedures. And, like Borman, Pratt and Putnam, this researcher will also be open to new and intriguing propositions that may emerge while she is "in the field." Being able to refocus the research process in order to follow-up on these emerging propositions is one of the advantages that the qualitative approach provides for the researcher.

As was discussed in chapter one, this research study will be using a systems' framework with which to guide the data gathering and analysis. Other qualitative researchers use general frameworks within which they study their subjects and assess their data. Implementing a rhetorical framework based on Burkean Theory (Burke, 1969), Sharf (1978) qualitatively analyzed the "relative success of leadership contenders in small groups in obtaining cooperation of the other members and resolving the struggle for leadership"(p.158). Using the analysis of audio tapes as her main methodology, Sharf determined from her study that certain leaders emerged because of their abilities to identify the divisions which had emerged in the various groups she was studying. These leaders also emerged because of their abilities to resolve group conflicts, to instill cooperation within the groups and to help the groups have a rhetorical vision and symbolic reality of themselves.

Participant observation is a technique that this researcher has used for the past two years and continued to use for the formal research process. It has become a necessary and essential qualitative tool in the study of the hospital and patient communities. Using participant observation in combination with other qualitative techniques such as interviewing and tape analysis provided this qualitative researcher with a powerful approach to studying the communication behavior of her subjects.

Phillipsen (1975 and 1976) used a combination of qualitative methods, including participant observation, interviewing, informants, tape recorded verbal interactions and all available data (filed records of speech behavior), in order to complete a three year study of "Teamsterville," a low income, blue collar neighborhood on the south side of Chicago. His findings included the conditions and places where men could and should speak as well as various cultural perspectives on the function of communication. Like Phillipsen, Liebow (1967) also used participant observation in order to study the interactional processes of people. For Liebow, however, the community he was studying was a one-block area of Washington, D.C. By becoming a daily participant observer, much as this researcher has been doing in her volunteer work as described in chapter one, Liebow was able to enter into the lives of his subjects and experience their worlds from their own perspectives.

All of these studies illustrate various advantageous characteristics that a qualitative approach has for studying people's communication patterns and behavior. In a family system experiencing a

life-threatening context, the qualitative approach, because of its flexible and sensitive techniques, can be adapted to the experiential world of those communication participants facing the crisis. The researcher approaches the patient and family alike with every effort to eliminate preconceptions, keeping an open mind to all that is going on around him or her. S/he has no specific hypotheses in mind, at least not at first, for the researcher takes an inductive stance; the substantive theory will be formulated during and after the gathering of the data and will, therefore, have more practical application for all involved in the life-threatening or dying processes.

Although remaining open-minded and sensitive to the communicating activities around him/her, the researcher, because of the qualitative approach, allows for intuition to play a part in the methodological process, using that intuition to create synthesized inductive data from which s/he can form hunches and gain guidance for the project. While intuition plays an important part for the researcher, the qualitative process and techniques enable him/her to slow down the intuitive process in order to be able to examine causal relationships between variables, based on the perceptions of the subjects ("Jane's illness has really caused problems for the family; we're really falling apart!"; (Jane) "I know I should be talking about my illness with my family, but I see no need to make a scene. They are all so emotional!"). The qualitative approach also enables the researcher to determine patterns and their function within the context and system of the subjects being studied. The "lived experience" that a qualitative

approach provides, allows for sudden revelations or changes of focus that may occur, another "adaptive" property which keeps the researcher flexible and sensitive to his/her research.

Summary. Persons in a change process, such as patients and families facing death, need to be viewed not only as statistics, but as human beings undergoing a unique, painful, and intimate process. Because the qualitative approach is derived from a more "inner" perspective of the human condition than are other methodologies, it can best fulfill the needs of the subjects and researcher alike, allowing the researcher to study his/her subjects without further adding problems to their situation. And, because of the natural and potentially sensitive tools that a qualitative approach provides, data gathered from the research experience can yield substantive theories that have practical application and yield insightful discovery for all those involved in the life-threatening or dying processes.

Review of Relevant Qualitative Studies: Content and Methodology

The qualitative tools that this research project used were interviewing with audio taping, participant observation and field note analysis.

As Schwartz and Jacobs (1979, p.38) note, "Interviews usually take one of two basic forms, structured or unstructured." In the structured interview, the researcher develops questions that s/he hopes will be relevant, unintimidating, appropriate, and data eliciting. The questions, as Lofland (1971) states, must be designed and posed in such a way as to not communicate a preferable answer.

The structured interview, through its well-planned and well-developed questions, tries to reconstruct the reality of the respondents' lives, viewing them as sources of "general information" which the researcher guides and probes in order to better understand that reality (Lofland, 1971).

In their study of adults' reactions to the death of a parent, Malinak et al. (1979) used a single, in-depth, semi-structured interview, which was ninety minutes long, to explore the reactions of fourteen adults (median age 32.4 years), who had lost a parent within the preceding 3-20 month period. In order to develop their questions and to give a framework to their results, the researchers used selected categorical concepts that they had reviewed from a study of pathological grief by Volkan(1970).

The study's interview questions centered around the theme of "Tell me about the death of your parent and your reactions" (Malinak et al., 1979, p.1153). The researchers taped the interviews, and all three members of the research team reviewed the tape recordings to reconstruct the "reality" of their respondents, cross-checking all judgments and impressions with each other.

The methodological techniques of this study are noteworthy because they allowed Malinak and his associates to understand what the "survivors" were experiencing without disturbing the personal nature of their grief and mourning process. Several of the categorical concepts borrowed from Volkan's research are also noteworthy because of the relevance and significance they have not only for survivors, but for"survivors-

to-be." Such selected categories as <u>identification</u> or <u>idealization</u> <u>of the deceased</u>, <u>ambivalence</u>, <u>coping resources</u>, and <u>favorable growth aspects</u> were suggestive of parallel responses that may occur during the death trajectory itself.

As Malinak notes, some family members may have a tendency to adopt some types of behavior or ways of thinking that make them like the deceased. This process, in this researcher's opinion, may begin before the actual death has occurred. A family's idealization of a dead person may also parallel their idealization of a patient facing a life-threatening crisis. Despite their "concurrent recognition" of the patient's "human faults and failings" (p.1154), family members and/or even friends and staff members may tend to idealize the patient because of his/her suffering or imminent death. On the other hand, some people, particularly family members, may feel "strongly charged affective ambivalence" (p.1154),another categorical response which can be applied not only to the survivors, but also to the survivors-to-be. Anger, guilt and depression can be strong reactions during the dying process, just as love, caring and concern can be. There may be times that family members may not know how they feel toward the dying person, and their confused emotional or mental states may cause them considerable difficulties or unhappiness.

The researchers concluded that there is a wide range of responses to the death of a parent, just as there is to the dying process of a loved one. For some, coping resources and mechanisms will be of utmost importance. And, as Malinak notes, many will grow from the dying/

death experience, finding a strength and resilience in themselves
that they didn't know they had. For others, the experience will only
be painful and stultifying. Malinak and his associates contend that
whatever the response, careful respect should be paid to individual
differences because of the very personal nature of the responses.
Using a similar methodological approach along with the suggested
categorical topics that were discussed also helped this researcher
to respect individual differences as she attempted to reconstruct the
"reality" of the patient and his/her survivors-to-be. Because of this
approach she was able to study her subjects without further
disrupting those lives and worlds which were already in a state of
crisis and/or change.

A qualitative study that covers another type of death, the death
of a dyadic relationship, also employs the intensive interview technique.
In his study of the "diseased states" that may occur in physically
healthy dyads, Bradford (1977) used interviewing and taping, and the
researcher's participant observation of twenty divorced men and women
from Parents Without Partners. The interviews, which lasted about
one hour and fifteen minutes, took place in the respondents' homes.
From his extensive field notes as well as the audio tapes, Bradford
created case studies which illustrated his subjects' responses. A
content analysis of the case studies and the responses suggested "nine
categories of problematic areas in marital dyads that ended in divorce"
(p.8). Several of these categories also have relevance for persons
experiencing their own deaths or the death of a loved one. As Bradford

noted, such areas as <u>communication</u> and <u>dominant/submissive</u> <u>behavior</u> can prove to be problematic for marital partners. If the marriage parti- cipants are facing a life-threatening crisis, these problem areas may become intensified. For example, a patient may become a victim of the dominant behavior exhibited by family or staff members. Another ex- ample can be seen in the situation that develops when communication between the patient and his/her family has become so difficult that <u>suppression</u> and <u>avoidance</u> are the results (i.e. "mutual pretense," "conspiracies of silence"). According to Bradford, suppression and avoidance, like the other problem areas mentioned, contribute to the emotional disintegration of a marriage; they are also indicative of the communication behavior that may occur when a relationship is experiencing a physical disintegration.

Although Bradford is not clear about what interview questions he used nor how he analyzed his content to develop the above-mentioned problematic areas, his methodological procedures should be noted be- cause of their sensitive approach to the very personal topic he was studying. The topic of dying, whether it concerns a life or a way of life, a person or a relationship, is an area that is lacking in qualitative research. As Schwartz and Jacobs (1979, p.53) note, there is a "crying need for sociologists to observe areas of social life that have hitherto been merely the objects of speculation or inferences, based on indirect information." The use of the interview and the tape recorder to study phenomena that has, heretofore, been merely talked or guessed about is most effective and practical. These

techniques allow the respondents, from the depths of their anger, frustration or despair, to share their feelings and opinions with an unknowing, curious and caring researcher. From that sharing, and the information and insight it can yield, will come the substantive theories and therapeutic interventions which will help others, as well as the subjects themselves, to understand and cope with the crises they are experiencing.

As was noted earlier, the preceding studies use a semi-structured type of interviewing, that is, an interview schedule that has some pre-chosen questions and much room for probing and follow-up questions and flexibility. Some researchers, however, use an unstructured type of interview, which this study also implemented during its preliminary observation phase.

Unstructured interviews assume that the interviewer does not know in advance "which questions are appropriate to ask, how they should be worded so as to be non-threatening or unambiguous, which questions to include or exclude to best learn about the topic under study or what constitutes an answer (what the range of answers to any question might be)" (Schwartz and Jacobs, 1979, p.40). The answers to the problems the researcher poses may emerge from these informal interviews, or even from the degree of rapport that the interviewer is able to establish during the interview (p.40).

During her work with cancer patients and their families, this researcher had many unstructured interviews with hospice patients, other patients, or with those she was merely observing. With each

open-ended question, the researcher became more sensitized to the range of responses and emotions that would follow. As the researcher became more knowledgeable about and more comfortable in the experiential worlds of medicine and life-threatening illness, she was able to ask better, more appropriate questions which elicited responses that would later help her develop her research format and interview questions. And,from her "casual chats" with people developed the direction and orientation for the research process itself.

Sudnow (1976), who will be discussed at length later in this section, put great importance on his "casual conversations" and informal interviewing of hospital personnel. From these conversations and his observations, Sudnow gathered important information about how death was being handled both physically and emotionally in a hospital setting.

While working with cancer patients and their families, Greene (1980) was aided in her attempt to better understand their needs and frustrations through her unstructured questioning of these people. From her experience and newly-found awareness,Greene developed practical and appropriate nursing interventions in which to help these patients and their families (such as crisis intervention techniques, coping interventions and anticipatory guidance interventions).

Casual conversation, unstructured, semi-structured and structured interviewing are building blocks of qualitative methodology. These specific techniques fall under a general heading that qualitative researchers know as "participant observation," which McCall and Simmons

(1968, p.9) describe as "a process in which the observer's presence in a social situation is maintained for the purpose of scientific investigation." Participant observation allows the researcher to become an active "participant" in the community or phenomenom s/he is studying. While "on the scene," whether observing or taking part in the experience of his/her subjects, the researcher uses her/his observational techniques to holistically study their situations and their communication behavior. And, from his/her participant observational experience can emerge propositions about the lives being studied.

McCall (in McCall and Simmons, 1969, p.36) notes that there are three types of propositions that participant observation is designed to draw upon: (1) Propositions discovered after the conclusion of data collection;(2) "emergent" propositions discovered while in the field; and(3) central propositions (the research questions). This study was designed to draw upon all three of these propositions. Through the research question, the researcher entered the field of interest to study the lives of her subjects and respondents. During those times of interviewing or observing, the researcher was able to be open to new and intriguing data because, as a participant observer, she was not structurally or theoretically bound up in her hypotheses or her methodology. There was time for flexibility and curiosity. And, while she was being satiated with information, she began to make sense out of her data, using her instincts, her cross-checks, and a constant comparative methodology, which will be discussed in the <u>techniques</u> section of this chapter. The propositional properties

of participant observation allowed the researcher to generate, inte-

grate and validate her data, and from this process came the sub-

stantive theory which helped to explain the once "unexplainable"

phenomena she had been exploring. A qualitative study which clearly

illustrates participant observation being used to "explain" phenomena

as well as to develop substantive theory is one done by Sudnow (1967).

Sudnow studied the social organization of dying as it concerns

the staff and members of two large hospitals. In his study of the

hospitals, he describes his role as an observer who "is trying to get

close to occasions of 'dying' and 'death', record what transpires in

the behavior of staff members of the institutions on such occasions,

and analyze some of the features of that behavior" (p.3). Sudnow's

research tasks, as he describes them are:

> to locate death and dying as organizationally relevant
> events, conceive of their handling as governed by the
> practically organized work considerations of hospital
> personnel and ward social organization, and sketch out
> certain themes which appear to bring together a set of
> observed facts about social practices relating to "dying"
> and "death" (p.3).

Sudnow gained access to his field of study through the hospital

administrators or "gatekeepers" of the institutions. They intro-

duced him to their hospital communities as "a sociologist studying

the social organization of the hospital" (p.6.). At one hospital he

dressed like a businessman, but in the other hospital, he wore a resi-

dent's gown which, as he states, was advantageous because it made him

less conspicuous and less subject to queries from the staff. Sudnow

notes, "The bulk of my time was spent watching and listening. When

possible to do so unobtrusively, I took notes in a small book. In other situations I made a practice of recording those occurrences I wanted to preserve as soon as I could get to a private place" (p.6). Most conversations were "casual," except for his rare interviews that dealt with technical matters. Then, he structured them.

As every participant observer must consider, Sudnow worried about the effect that his presence would have on the behavior of his sub-jects. But, as he notes, even though hospital personnel at first seemed to act as if to show him what they thought he wanted to see, the longer he stayed there and "hung around," the more people took his presence for granted.

Sudnow's study is a prime example of a researcher who used casual conversations and his observations as his main sources of information. From those data resources, Sudnow developed theme categories which helped to explain the medical world he was observing (i.e. "The Techniques of Breaking Bad News," The Processing of Bodies," and "The Care of the Dying").

Like Sudnow, Leadon (1980) studied a medical setting, except from a communication perspective. Her participant and nonparticipant observing, along with her interviewing methodology, helped her to describe different types of communication patterns and rules that function within a certain setting or context of a hospital. Using Lofland's (1971) scheme of the arrangement of phenomena (acts, acti-vities, meanings, participation, relationships, and settings) for a framework for her study, Leadon developed her questions along a theme

of "microscopic" ("What is your job here?") to "macroscopic" (What goes on here?"). Using this procedural scheme, Leadon concluded that communication rules seemed to be functioning in three different categories or contexts--the dying patient, research, and internal staff relationships. More importantly, though, is Leadon's use of a framework itself in which to gather and assess her data. Like Leadon, this researcher also used a framework that guided her data gathering and assessment. The systems approach combined with hypothetical categories developed from the researcher's two year participant observational experience (using the constant comparative method) helped to frame this study's exploration of communication patterns during crisis situations. And, as was seen by Leadon's study, this qualitative researcher's use of such methodological tools as interviewing and participant observation helped her not only to discover communication patterns, but also helped her to discern how these patterns (and rules) functioned for the participants of a given context.

In her study of the sexual concerns of cancer patients, as noted in chapter one, Johnson (1976) states, "The use of interviews to examine the effects of cancer on patient relationships appears helpful. Furthermore, the limited numerical results of this initial study do not fully reflect the intense and complex communication that took place during these interviews. There has been, for example, continued contact between the interviewer and patients and spouses, until the onset of death in some cases" (p.187).

As Johnson implicitly states, the study of communication is a

complex research process. The studies reviewed in this section have illustrated some of the different tools that this study, as well as many other qualitative projects have used to explore and examine the complex communication phenomena which functions in each person's living and dying processes.

The Pilot Study: Description of Procedures

The pilot study for the present research was conducted on two different weekends in October, 1981. Two sets of married couples, each of which had one spouse who had cancer, were the subjects for the pilot study, although an original couple which had consented to be interviewed by the researcher withdrew from the project because of the husband's sudden physical deterioration and subsequent death.

Entry. The subjects for the pilot were contacted in two different ways. The first couple became subjects of the study as a result of the researcher's ongoing contact with them through the hospice program. Upon hearing that the researcher would be doing a thesis which would be studying couples' perceptions and experiences while going through cancer, the wife, who was in the last stages of her cancer, volunteered to be interviewed. After discussing the project with her husband, he, too, agreed to participate in the interview project. The researcher than contacted both husband and wife to personally discuss her project and interview techniques (taping, length of interviews, appointment schedule) with them and to get their verbal consent for the project. Because of the friendship between the couple and the researcher, it was deemed unnecessary to discuss the researcher's background and experience in the area of

her research. When discussing the interview, the researcher was careful not to give too much information about the project, talking, rather, in general terms about the pilot ("I want to know what it's like for you as you go through this cancer experience.").

The second couple was contacted with the cooperation of the hospice director and the cancer outpatient clinic nurse (also a member of the hospice team) at Columbus Hospital, in Great Falls, Montana. When the original second couple withdrew from the pilot, the researcher called the hospice director in order to find a new couple. The director, having no couple under hospice care at the time (except for one couple in which the cancer had affected the mental stability of the patient to the degree that he could not be interviewed), contacted the nurse in the outpatient clinic, who telephoned the researcher in Missoula to tell her that she had a married couple in mind, but needed more information about the project.

In discussing the interview situation specifically, and the project in general, the nurse and the researcher made the following decisions:

1. The nurse or some other resource person would make the initial contact in order to insure the patient and spouse that the hospital or other such institution was not carelessly or secretly giving out patients' names, addresses and/or phone numbers to anyone who requested them to. This aspect of confidentiality also allowed the couple to refuse the request of being interviewed without the researcher ever knowing their identities.

2. Initial contact by a person, (such as a nurse, doctor or other caregiver), who is already a part of the couple's cancer experience, was thought to be advantageous to the researcher in order to build her credibility with the prospective subjects. In essence, the researcher felt that if the nurse was excited about the project, she would reflect that feeling in her discussion with the couple. If the couple had fear about the project ("What are we getting ourselves into?"), those fears could be alleviated by the fact that someone they knew and respected, and who had been working with them during their life-threatening crisis, was discussing and promoting the project with them, relating not only initial information about the project and the researcher, but also re-lating her positive attitude about the interview situation.

3. The researcher felt it was desirable to trust the judgment of the nurse (or other resource persons) concerning her choice of sub-jects because she had been working with the couple and had formed general opinions and/or impressions about their willingness and availability to talk.

During the initial contact, the nurse conveyed the following general information, following a format suggested by the researcher.

> Mary Zartman-Nelson is one of our volunteers at the clinic who is now in Missoula working on her master's degree in Interpersonal Communication. For her thesis, which is the research project she is working on now, she wants to know what married couples go through when one of the spouses has cancer.
> She contacted me because she's looking for people to interview who would be willing to talk about their experi-ence, and thought I might have some people in mind. Does this interest you? Would you be willing to talk to her? If so, I'll have her call you, since she's in Missoula,

if you don't mind me giving her your phone number.
Then, she can tell you more about herself and her
project.

The nurse also told the researcher that she talked very positively about the project with the couple, which seemed to alleviate some of their "fear of the unknown." During her discussion with them, as she also related to the researcher, the couple remembered who the researcher was from their visits with her in the waiting room, which also seemed to contribute to their positive attitude about being respondents for the interviews.

Upon hearing from the nurse that the couple was willing to be interviewed, the researcher called the couple, and in her discussion with the wife covered such topics as interview appointments, length of interviews, approval for taping, researcher background, and common interests, such as hospital volunteering. The researcher noted that whenever the conversation centered around the topic of the interview or her husband, the wife lowered her voice, and because of this, the researcher inquired several times as to how the husband felt about being interviewed ("It will be fine."), and if she should talk to the husband about the project ("You don't have to; I've already talked to him.") Because the husband was the one suffering from cancer, the researcher wondered about the decision-making process that was going on (Was she deciding for him? Was he just "going along?" Was he not feeling well, or near death, and was she not telling him? Why was she whispering??!!) Despite the researcher's unanswered questions, and her seemingly "blocked" access to the husband, she decided to do the

interview with the couple anyway.

Interviewing Formats. The couples were interviewed using two different formats: (1) the couple together (day one), then the couple individually (day two), and (2) the patient and spouse separately (day one), then the couple together (day two). The researcher used semi-structured interview schedules for all interviews. Follow up interview schedules included probing and cross-check questions which were developed from the initial interview responses. The reseacher listened to the audio tapes of the initial interviews in order to develop these questions.

Upon entering the homes of the respondents, where all interviews took place, the researcher again went over basic information about the interview procedure, discussed questions and concerns, and decided with the couples as to an appropriate place for the taping and the tape recorder. In all sessions except one, the living room was chosen by the couples as the setting for the interviews. However, the male patient in the second couple decided that he would be most comfortable in his workshop in the garage, so he would be able to work and talk at the same time.

Before starting each interview, the researcher again discussed the area of confidentiality, telling her respondents that only she and her adviser would listen to the tapes, that what was said in individual interviews would not be shared (spouse with patient, or vice-versa), unless one of the spouses wished the information to be passed along through the interviewer to the other spouse, and that all identifying

information (names, descriptions, situations) would be changed before the publication of the results. And, because of the presence of cancer, special attention was given to planned or unplanned breaks for the patients, although, as it turned out, no breaks were taken in any of the interviews because no one wanted or needed them. The researcher also told her respondents that if any of the questions made them feel uncomfortable or made them wonder what was being asked, they should feel free to simply not answer, to express their discomfort or confusion, or to ask for clarification.

At the beginning of each initial interview, whether it was a couple or individual interview, the researcher wrote down some demographical data about the respondents, and then, while keeping the flow of the conversation going, turned the tape recorder on, trying to call as little attention as possible to the act so that the respondents would soon be able to forget the recorder was there (which they seemed to do). The interview questions themselves were kept open-ended and broadly stated so that they could fit into the conversational stream. Using a semi-structured interview schedule allowed the researcher to be able to skip around, back-track, dismiss, and develop questions that seemed appropriate and information-eliciting. Yet, the schedule also gave her a guide of pre-chosen questions on which to depend. During couple interviews, the researcher constantly tried to bring both dyadic participants into the conversation by using open-ended, reflective types of questions, such as, "And, how do you feel about that, Jim?", or "Maybe you could add to that, Jane." In follow-up interviews, the

researcher used questions such as "Jim, you mentioned that....Do you want to talk any more about that?" (The researcher had to handle this _very_ carefully when the follow-up interview was the couple in order that no confidences would be broken concerning the spouse/patient interviews, which would put the respondent on the "spot.")

After the interviews were over and the tape recorder was turned off, the respondents and the researcher informally "chatted" about the interview experience, with the interviewer asking for and receiving feedback on the questions and procedures for the session. In all sessions, these times of unstructured interviewing proved to be extremely valuable because of the information and comments that were expressed not only about the interviewing process, but, more importantly, about the respondents' feelings, experiences, and relationships.

After leaving the respondents, the researcher would, as soon as possible, write down her impressions, points of interest, bits of dialogue, nonverbal activities and other information which she thought would be important to understanding the session. And, when necessary, she would listen to the tapes in order to develop questions for follow-up interview sessions.

From the six interviews, the researcher received first-hand experience which helped her to develop the general orientation and format for her final study.

The Pilot Study: A Learning Experience

From the pilot study experience, the researcher learned the following things, which she incorporated into the final procedures

for the research project itself.

1. In experimenting with the format of the interviews, the researcher found it easier and more effective to question the couple together and then individually. This format enabled the researcher to view the marriage partners, firstly, as they related/reacted to each other (their "system"), and, secondly, it enabled the researcher to privately cross-check or follow-up on each person's responses, feelings, and nonverbal behavior which occurred during the initial interview. Using this format also allowed each respondent to give reactions and personal responses to communication behavior and dialogue used by his/her partner or by the respondent, without interference, interruption, or without affecting confidentiality, something which could not happen using the opposite procedure.

2. As Bogdan and Taylor (1975, p.105) note, "It is at the beginning of the project that the tone of your (researcher and respondent) relationship is established." Using a resource person for the initial contact of a couple whom the researcher did not know personally did help to establish the "tone" of the project and the relationship of interviewer and respondent. For the project, this researcher made use of all resource people possible for the initial contacts for her entry phase into the lives of her respondents. She also gave these resource people typed descriptive formats which they used to tell their prospective subjects about her and her project.

3. Also, in the initial entry phase, the researcher, when it was possible, contacted both marriage partners concerning the interview.

This was done in order to avoid confusion on the part of the subjects, as well as to assure the researcher that <u>both</u> spouses wanted to be interviewed. Doing this whenever possible helped the researcher to avoid situations which may have arisen in which one spouse, because of her/his enthusiasm, interest, or power of decison-making, could or would have spoken for the other spouse in consenting to be interview subjects In this case the "tone of the relationship" between interviewer and respondent would have become strained if the respondent had not really wanted to be in the interview situation, but was just "going along" with his/her partner.

4. Interviewing the two couples made the researcher realize how much <u>attention and consideration had to be given to the physical state of the patient and to the schedules of both partners</u>. Trying to fit an interview into the subjects' daily lives proved to be frustrating and disappointing, but the state of health of the patient and the lives of the subjects had to be given top priority, which took much patience and flexibility on the part of the researcher. The pilot study also showed that no interview took more than an hour and a half. The researcher pondered this but came up with no specific conclusions. However, she did decide to work on asking more and better questions, which would guide the subjects into being even more responsive. Because of this, she still decided to ask her respondents to schedule two-hour block appointments. If the interviews ended early, then there was time to informally "chat" with the interviewees.

Besides appointment schedules and length of interviews, the researcher felt that the <u>setting for the interview</u> as an important factor

contributing to the ease and responsiveness of the respondents. Having

informally interviewed patients in a hospital setting, the researcher

found a home setting to be much more comfortable and less-restrained for

all involved in the interview session. Even though a home setting has

all the disadvantages that daily life can bring--noise, interruptions,

and lack of privacy, it is still a more desirable setting because of

the freedom and comfort that its inhabitants can feel, a general re-

action that usually precipitates better responsiveness to and enjoy-

ment of the interview session.

6. Besides viewing the setting as a practical consideration, the pilot

study also taught the researcher a very valuable lesson--do not use 120

minute tapes for interviewing. As Bogdan and Taylor (1975) suggest,

this researcher did make sure that her equipment was functioning properly

before each session, but, in listening to the audio tapes of the spouse

and patient interviews (second couple) in order to develop new questions

for the follow-up interview, the researcher discovered, much to her

distress and frustration, that the tape had broken while she was starting

and stopping it. Because the patient and the spouse interviews were on

both sides of the tape, she lost two interviews. After spending an

entire afternoon trying to splice the tapes, she, instead, went through

the interview questions herself and tried to reconstruct the various

answers from memory, since she had not taken any notes during the inter-

view, another valuable procedural change that she adopted for her formal

research process. Her "reconstructed" answers, combined with the notes

that she wrote immediately after the session, seemed to adequately cover

the interview, under the circumstances. But, she learned to use sturdier, shorter tapes, even though they had to be turned over in the middle of the session. The slight interruption was worth the valuable dialogue that a tape recorder produced and preserved.

7. Another important point learned from the pilot was the choice of interview questions which would be included in the regular study. The respondents' responses, as well as their feedback on the questions helped the researcher to choose, delete, and/or restructure questions for the final interview guides, which will be discussed in the techniques section of this chapter.

8. Finally, from doing the pilot, the researcher learned that one is supposed to get signed approval for taping. This is something she did not do with her respondents, but which she did for the final study.

The pilot study proved to be very exciting and informative. The researcher was constantly aware of how she had to be "on her toes" in order to formulate open-ended questions which would probe and cross-check, yet not stifle the flow of conversation. She also learned the importance of the interviewer suggestions that Bogdan and Taylor (1975, pp.112-113) make:(1) don't interrupt,(2) pay attention,(3) be non-evaluative, and (4) be reflective. These talents and/or abilities help to make a successful interviewer out of anyone.

Procedures for Gathering Data

The procedures for this study were enacted two years ago, when the researcher began using a participant observer mode in her work with cancer patients and their families. Whether she was serving

coffee in the waiting room of the cancer outpatient clinic or was at the bedside of a patient in his/her hospital room or home, the researcher kept mental notes of her thoughts, impressions and bits of dialogue which she later transcribed into field notes and a journal. From her two year experience, the researcher developed the following formal research process, which includes participant observation, and semi-structured and unstructured interviewing.

The final interviewing part of the research project covered a five month period, running from January, 1982, through mid-May, 1982. During this time, the researcher did ten couple interviews and twenty individual interviews, which lasted not less than one hour and not more than two hours.

The interview procedure began with the initial contact by the resource person, who used an introductory format similar to that discussed in the pilot study. If the respondent gave a positive response to the resource person, then the researcher made a follow-up contact, either by phone or in person, at the respondent's convenience. That discussion covered such items of interests and concern as (1) the researcher's motives and intentions, (2) anonymity, (3) final say, (4) overall plan, and (5) logistics of getting started (Bogdan and Taylor, 1975), while also addressing any questions the subjects might have had.

From that discussion, the researcher and subjects decided on an appointment schedule which included an initial two-hour block in which the couple was interviewed, and two, two-hour appointments in which the spouse and patient were interviewed individually. The appointment

schedule, out of necessity, included time after the first interview for the researcher to listen to the audio tapes of the interview, from which she developed interview questions (probing, follow-up, and cross-check) for the spouse/patient interviews. Scheduling appointments over a two day period was the most conducive to the research process, but the researcher, who remained sensitive to her subjects' needs and wishes throughout the interview process, scheduled interviews as far as two weeks apart.

Once the researcher entered into the interview setting, she informally talked with the subjects, discussing the project in honest but vague terms, and again discussing interview procedures and problems. At that time she also had the couple sign a statement which showed their written approval for the taping of the interviews. During this time the researcher also "chatted" with her respondents about incidental things (i.e. weather, house, politics), in order to put subjects at ease and in order to establish rapport between the couple and herself. At that time, she also asked them the demographical questions contained on the facesheet, including two other questions that the original facesheet did not contain--(1) years married, and (2) educational background (see Appendix A). As Lofland (1971) notes, beginning an interview situation with a discussion about relatively neutral topics such as those mentioned can be an "innocuous way of getting into the question-and-answer process" (p.79).

During the interview, the researcher questioned both marriage participants, using a semi-structured interview schedule, while also writing down notes or questions covered, verbal and nonverbal communication,

important quotes, and different personal impressions and feelings. At different points in several of the sessions, breaks were taken when the patient's physical state required them or if the couple/spouse so desired them.

After the interview, the researcher turned the tape recorder off, and informally discussed any questions, concerns, feedback, and any additional comments with the couple. After leaving the respondents, the interviewer wrote down her impressions of the interview, along with notes on emerging themes and subjective feelings, as well as notes on communication behavior and dialogue (Bogdan and Taylor, 1975). She then listened to and transcribed the tapes from the interview. Individual interviews were handled the same way, except for the filling out of the facesheet, which had already been done.

After two sets of couples had been interviewed, the researcher analyzed her journal, notes, and pilot study tapes in order to develop general clusters of categories (the constant comparative method). These categories suggested a general framework with which to view and analyze future interview responses and participant observation notes. Finally, after the interviews were completed, the formal data analysis began, although the researcher used the constant comparative method throughout the research process in order to generate and integrate categories of responses.

Specific Techniques for This Study

Interview. The first technique that this study used was interviewing,

both semi-structured and unstructured, as described in the section on

methodological reviews of qualitative studies in this chapter. Pro-

cedurally, the unstructured interviewing took place before and after

the interview sessions, while a semi-structured interview schedule guided

the interviewer and her respondents through the interview process itself.

Instrumentation. Schwartz and Jacobs (1979, p.44) describe four

types of questions which might be employed in an interview schedule:

1. Questions decided upon in advance with fixed choices
   for answers.

2. Questions decided upon in advance which are "open
   ended" with respect to answers.
   a) Questions of this type with provisions
       for future questioning or "probes"

3. Questions which are not decided upon in advance
   but which are asked spontaneously during the
   interviews because they appear relevant or important.

The interview guidelines for both couple and spouse/patient (see

Appendices B and C) contexts contain questions which are a combination

of Schwartz and Jacob's second and third statements of description.

Having those types of descriptive questions allowed the interviewer to

"fit" them into the conversation, while also letting the respondents

approach and answer the questions from their own perspective. If a

topic came up or a statement was made during the session which the in-

terviewer wanted to follow-up on or probe, the semi-structured quality

of the interview and the open-ended structure of the questions allowed

her to do this. Schwartz and Jacobs describe these qualities as "re-

cursively defined," which they describe as the extent that what has

already been said in an interview is being used to determine or define

the next question to be asked (p.45). They contend that "making inter-viewing recursive allows the researcher to treat people and situations as unique and to alter the research technique in the light of information fed back during the research process itself" (p.45).

Because she had recursive interview schedules and questions, the researcher was able to treat each couple and each individual as unique human beings with unique experiential worlds. Although each guideline had some pre-chosen questions, they were broadly stated and open-ended which was evident in the number of probing sub-questions included with most questions. As each couple and individual was being interviewed, the researcher was able to adapt, restructure, delete or develop new questions to fit the unique experience of the respondents.

Several new questions were developed, either from the thesis com-mittee members' suggestions or from early interviewers' responses, and these questions were permanently added to the interview schedule. They included "How has the illness changed your relationship?" "How do you comfort each other?" and "How has the illness affected your physical relationship with each other?" The last question was asked only during the last four couples' individual interviews because the topic of cancer and sexuality was first discussed during the sixth couple's interview situation.

Taping. During the interview, the researcher taped all but three respondents so that she could keep her full attention "focused upon the interviewee" (Lofland, 1971, p.89). Taping the interview also allowed the researcher to focus on formulating new and relevant questions and

probes, to concentrate on actively listening and paraphrasing, and, generally, the taping of the interview enabled the researcher to give complete attention to the respondents' responses and nonverbal communication. In two of the three untaped interview situations, the researcher was unable to use a tape recorder because of the physical settings and their inadequate electrical outlets. In the third interview that was not taped, the patient's death was so imminent that the researcher felt it was inappropriate to bring a tape recorder into the situation. In all three of the untaped interviews, however, the researcher took extensive notes about responses, both verbal and nonverbal.

Lofland (1971) discusses one danger in taping--not listening to the interviewee because one assumes that the tape is "getting it all." But, as Lofland discusses, "One device for fighting against this tendency is to take sparse notes--key sentences, key words, key names etc.--in the course of the interview itself, to keep account of what has already been talked about and what remains to be talked about. Having the advantage of the tape recording, this becomes note taking at its best" (p.89).

In order to take notes on each specific session, the researcher had interview guides copied so that she had a fresh copy for each session. After the taping, the interviewer transcribed the tapes, deleting sections of the dialogue which she felt had no content or relational information for her project. She cross-checked her results with her adviser, who also followed the same procedure in several instances, as a reliability check for the deletions.

Analysis of past participant observational notes. As was noted in

the procedures portion of this chapter, after doing two sets of inter-

views, the researcher analyzed her journal and field notes, using a

"constant comparative method." It is a method that contains four steps:

1. comparing incidents applicable to each category
2. integrating categories and their properties
3. delimiting the theory, and
4. writing the theory (Glaser, in McCall and Simmons, 1969, p.220)

For the analysis of the researcher's field notes and journal, she

started by "comparing incidents" and clustering these incidents, com-

ments and observations into general "theme" categories. She then used

these general categories as a beginning framework in which to analyze

data from forthcoming interviews and observations. This framework also

allowed her to generate and integrate new categories as she went along.

Using the constant comparative method during her data gathering phase of

the study helped to build the foundation on which her substantive theory

was later developed.

Participant observation. The final method that was used for this

study, participant observation, also helped to build the foundation for

substantive theory development. "Participant observation enables the

research worker to secure his data within the mediums, symbols, and

experiential worlds which have meaning to his respondents" (Vidich, in

McCall and Simmons, 1969, p.79). For two years this researcher has used

this method of qualitative study in order to understand people and their

patterns of living and dying. Participant observational techniques, such

as informal interviewing, and direct observation and participation have

allowed this researcher to enter into the lives and experiences of those

who are facing the possibility of death, those who are dying, and those who will be left behind. In working with these people, the researcher became a part of their world, conducting herself in such a way that the events that occurred during her observations did not significantly differ from those which occurred in her absence (McCall and Simmons, 1969).

For this study, the researcher continued to do her participant observation, using this technique to understand the "holistic" life situation of her respondents (Lofland, 1971). And, as she had done in the past, the researcher continued to write field notes about her observations and interviews, for as Bogdan and Taylor (1975, p.60) posit, "Systematic and analytical participant observation depends on the recording of complete, accurate and detailed field notes," notes which are important in the constant comparative method and the development of substantive theory.

Subjects

As Bogdan and Taylor (1975, p.103) contend, "Most subjects are not 'found,' but rather, emerge in the course of the researcher's everyday activities." In the two years of participant observation that this researcher has done, she has observed and talked to many subjects, including hospital administrators, doctors, nurses, patients, families, hospital technicians, housekeeping personnel, ministerial and pastoral care members, secretaries, and hospice team members. She obtained access to her "field" by initially requesting permission from the hospital administration, or as Bogdan and Taylor (1975, p.31) refer to them, the "gatekeepers" of the organization. It is through these

gatekeepers that the researcher was accepted into the hospital community and was directed into channels in which she could find resourceful contacts, such as the pastoral care and cancer outpatient departments, and the hospital's hospice organization.

But, the setting that seemed to be the best resource for subjects was the cancer outpatient clinic's waiting room. It is in that room that the researcher was able to listen to and talk with patients of all ages and with all types of cancer. While the patient was receiving his/ her treatment, the researcher would sit and visit with the family members and/or friends, or she would just simply listen to other patients and relatives conversing.

From these weekly experiences, in particular, "emerged" many of the subjects whom the researcher informally interviewed and studied. Several of these subjects later became the researcher's hospice patients, and she was able to share their dying process with them and with their families.

Respondents

Respondents for this study were ten married dyads, each of which had one spouse with cancer. Marital dyads were chosen because of their availability and willingness to talk, with the following stipulations. Neither patient nor spouse was to have been under the influence of strong drugs or medications, that were interfering with his/her ability to think, react, and respond to the interview questions. And, the patient's physical deterioration should not have reached the point that his/her mental stability had been impaired. These two stipulations were considered under the advice or judgment of a medical professional.

Although the researcher had planned on using all resource people possible in order to find subjects for her research, it was not necessary to do so because of the very positive response and active cooperation of the Columbus Hospital oncology nurse and chemotherapy doctor. All initial contacts with the respondents were made by these two resource people, using the general introductory and informational format which was described in the pilot study. After a positive contact had taken place, the follow-up contact was then made by the researcher. Of the sixteen couples contacted, the ten who agreed to do the project became its respondents.

Materials

Materials for the research consisted of ten interview schedules for the couple interviews, twenty spouse/patient interview schedules to cover the individual interviews, ten facesheets on which to record demographical data about each couple, and ten consent forms for the couples to sign to show their written approval for the taping of the interviews. A tape recorder (with a counter) and ninety minute tapes to cover thirty interviews was also implemented, along with a clipboard and other writing materials with which to write "unobtrusive" data. For the purpose of field observation, analysis and/or transcription, 4x6 cards and card files also were used. Finally, the researcher had extra tapes on hand to be used if necessary, although none were needed.

Special Problems

Because of the sensitive topic of this research, entry into the subjects' lives and experiential worlds was done with care and consider-

ation. Attention was given to the physical and mental states of both patient and spouse, and although the researcher anticipated the factor of subject mortality entering into her study, as was shown from the pilot study, no respondents died before she was to interview them. However, several were very near death at the time of her meeting with them and have since died following the interviews.

Interview questions were kept open-ended and broadly stated so that they could apply to each couple's unique experience. And, as Lofland (1971) notes, the interviewer tried to keep her questions worded so that she was not phrasing them in such a way as to communicate what she believed to be the "preferable answers" (p.85). Scheduling of interview appointments also proved to be a problem, as was discussed in the pilot study, but the researcher was able to work out any scheduling difficulties with each respondent.

Another problem that was anticipated concerning the interview process was the difficulty which may arise if the respondents refuse to be taped. Although many people seem to be nervous around or afraid of tape recorders, none of the respondents expressed any negative reactions or fears about being taped. And, one couple even expressed a desire to have their tapes after the researcher was finished with them, to which she consented.

The final, and perhaps the most important problem that the researcher anticipated for this project was the availability of subjects who would be willing and able to talk to the researcher. However, this problem did not materialize during the formal research process, again, due to the cooperation of the Columbus Hospital oncology department in finding

prospective subjects for the researcher. As Bogdan and Taylor (1975, p.103) note, "It is through involvement in other communities that one establishes the kind of reputation and contacts necessary to meet and recruit ideal research partners." The researcher's two-year involvement with the hospital and hospice communities aided her in her task of making use of those resource people who directed her in her search for subjects.

Analysis of Data

Bogdan and Taylor (1975, p.79) note that, "Data analysis refers to a process which entails an effort to formally identify themes and to construct hypotheses (ideas) as they are suggested by data and an attempt to demonstrate support for those themes and hypotheses." As was noted in the techniques section of this chapter, the constant comparative method (Glaser, in McCall and Simmons, 1969) of qualitative research was used as an ongoing process of data analysis throughout this study.

The constant comparative method of investigation is concerned "with generating and plausibly suggesting (not provisionally testing) many properties and hypotheses about a general phenomenom" (Glaser, p.219). The steps of the constant comparative method, as discussed in the techniques section, are designed to aid the qualitative researcher in the attempt to generate a theory which is "integrated, consistent, plausible, close to the data, and, in a form which is clear enough to be readily, if only partially, operationalized for testing in quantitative research" (Glaser, in McCall and Simmons, 1969, p.218).

This researcher first started using the constant comparative method

during her preliminary analysis of her field notes. At this time, the researcher read over her field notes from the past two years. She then wrote notes about recurring themes and clusters of general topics or theme categories that she discerned in the notes (Bogdan and Taylor, 1975). The researcher then implemented a coding/categorizing procedure which involved the following steps:

1. She read through the data, wrote down general themes/topics that seemed to be important, and assigned letters (or a letter) to them. For instance, a general topic that occurred from her field notes was "coping behavior," which the researcher designed, in pencil, as a "cb" on her topic card.

2. The researcher then typed "incidents" (dialogue, interactional or behavioral descriptions, impressions) onto index cards, only putting "bits" of description or excerpts of dialogue onto the card. By using this procedure, the researcher did not, for example, end up typing an entire conversation onto a card, but would, instead, type various statements from the dialogue onto different cards in order to separate out ideas.

3. The researcher then dated and coded the card according to its topic. As was noted in step one, the topic titles were done in pencil. This allowed the researcher to be flexible about changing the topic of the category if and when the data precipitated the change. The code on the card also included the methodological technique that was used to gather the data (i.e., "S.I." - semistructured interview, "P.O." - participant observation).

4. When typing up the "incident" onto cards, the researcher used carbon paper in order to be able to duplicate her cards. Because of this she was able to file each incident card into more than one category of analysis, if necessary. In doing this, the researcher followed the defining rule of the constant comparative method, "While coding an incident for a category, compare it with previous incidents coded in the same category" (Glaser, in McCall and Simmons, 1969, p.220).

As Glaser notes, this ongoing process "very soon starts to generate theoretical properties of the category" (p.220). He advises the researcher, at this point, to think about how a category, including the incidents it contains, relates to the other categories. In order that the researcher should not get "stuck" in her categories (filing every new incident into the same category or wondering what incident goes where), she stopped coding and recorded a "memo on ideas," to give fresh energy and thought to her research analysis. She also, at several points during the preliminary analysis, consulted with her adviser about the emerging categories and their properties that she was finding.

After using the coding/comparative method to organize and analyze her past field notes, the researcher then approached the incoming data produced by her formal research techniques in the same manner. As new information was gathered, the researcher began comparing and generating new categories, while also integrating some of the categories and their properties under existing topics. The researcher was, however, careful to code and analyze her audio tape data and her process notes separately.

As Glaser notes, in the beginning, each incident is compared with each incident in order to form a category, but as analysis continues and informal data keeps coming in, the researcher changed her focus from comparing incidents to comparing an incident with the properties of the category (a category which was formulated from the comparison of the incidents). As a result, "...the accumulated knowledge on a property of the category--because of constant comparison--readily starts to become integrated; that is, related in many diverse ways, resulting in a unified whole" (Glaser, in McCall and Simmons, 1969, p.222).

From this comparing, generating and integrating of incidents, categories and categorical properties, the researcher developed major categories ("unified wholes"), which have much supportive evidence from the study's data, minor categories, which have some supportive evidence, and what this researcher termed uncoded data, which was kept until the final analysis, but was not categorized until then, if at all.

Methodological Concerns

Reliability. In the qualitative exploration of communication phenomena, the reliability of the data is of utmost importance to the researcher. Deutscher (in Filstead, 1970, p.202) notes that "The concept of reliability...concentrates on the degree of consistency in the observations obtained from the devices we employ: interviews, observers..." The primary procedure used to check the reliability of this study was the ongoing comparison of the "degree" of consistency" of observational and interviewing data (behavior and response). In order to answer the question- "Are the different techniques coming up with the same type or complementary

type of data," the researcher instilled the following reliability checks into her study:

1. The researcher used the constant comparative method to analyze results and categories derived from the different techniques used in the study.

2. The researcher met with her adviser throughout the research process in order to cross-check the constant comparative method and its results. The researcher also used a judge throughout the categorizing process to help her work through the overwhelming amount of data, to guide the constant comparison of the categories, and to cross-check her results with the judge's results.

3. Behavioral and verbal responses of the respondents to the pre-chosen questions of the interview schedules were compared (comparing the ten couple interviews with each other, and comparing the twenty individual interviews with each other).

4. During the final analysis, the researcher used two judges (a) to generate categories for uncoded data or to fit that data into existing categories, (b) to judge highly subjective or problematic categories (as agreed upon by the researcher and her adviser), and (c) to judge categories that the researcher was fairly certain about.

5. In their analysis of problematic or highly subjective categories, the researcher had one judge generate completely inductive categories from the sample of data cards that she was given, and she had the second judge sort the same data cards into pre-chosen categories. This process provided an additional reliability check for the study.

6. For categories that the researcher was fairly certain about, she gave the judges clusters of data, while asking them such questions as "What similarities are there in these cards?", or "Which ones don't fit? Why not?."

7. The reliability of the two judges' results was tested through a comparative method of analyzing their categorization similarities (inductive vs deductive) and the consequential percentage of "matched" results, a process which is discussed in more depth in chapter four - "Presentation of Results."

8. The randomization procedure used for card selection and categorization for the judges involved the following steps: (1) the researcher shuffled and reshuffled the cards in each of her separate categories; (2) she then chose ten cards off the top of her card "deck" from each category, unless there were fewer cards than ten in that category. In that case she took all the cards from the category, noting the amount as she did; (3) she then put all cards together and shuffled/reshuffled before giving them to Judge A for the inductive judging. She used this same randomization procedure, as a reliability check, for Judge B, using all new cards except for these categories which had fewer than twenty cards.

9. Because of the length of the study, two and a half years, the researcher was able to give a longitudinal framework to her results, a reliability check that helped her determine if patterns of behavior and responses occurred "not once, but repeatedly" over time (Neale and Liebert, 1973, p.97).

10. Finally, the researcher used the constant comparison of participant observational notes with what the respondents said was happening

to check on the reliability or the "degree of consistency" in the re-
search data gained from using the different methodological techniques.

Validity. Also of vital concern to the qualitative researcher is
the validity of his/her research design and conclusions. As Kazdin
(1980, p.34) notes, "The unique contribution of an experiment is that
it helps rule out different variables that might explain a particular
phenomenom." In qualitative research, as well as in quantitative analy-
sis, the researcher attempts to establish conclusions from research
designs that are internally valid. As Kazdin further states, internal
validity refers to the extent "to which any experiment rules out alter-
native explanations of the results" (p.34). Validity addresses such
questions as whether "a difference exists at all in any given comparison.
It asks whether or not an apparent difference can be explained away as
some measurement artifact" (Bailey, 1978, p.60). Internal validity also
asks such questions as, "Is this a product of bias or researcher effect?",
or "Is this really a concept or a category?" When developing an experi-
mental research design, the researcher must take into account any factors
or sources other than the "independent variable" that could explain the
results. Such factors or sources are called threats to internal validity.
It is essential for this researcher to discuss potential threats to her
study's internal validity in order to minimize "the ambiguity of the con-
clusions" that can be drawn about the research process (Kazdin, 1980, p.
34). The following analysis will then conclude with a discussion of the
internal validity checks she used to counteract these potential threats.

Threats to Internal Validity in the Present Study

History. "This threat to internal validity refers to any event occurring in the experiment or outside of the experiment that may account for the results. History refers to the effects of events common to all subjects in their everyday lives. The influence of such historical events might alter performance and be mistaken for an effect resulting from the intervention or treatment" (Kazdin, 1980, p.34). The cancer crisis is, in effect, an event that has created the context in which the research process will take place. But, other circumstances or events may occur which affect the way the respondents talk about their crisis. Such factors as the sudden remission or deterioration of the patient may affect the response process. In a very practical sense, the interview sessions themselves may be affected by outside events (i.e., disruptions, lack of privacy). These types of "historical events" were noted and taken into account when addressing the issue of internal validity.

Maturation. Maturation is often combined with history as a threat to internal validity. Maturation refers to processes of change that occur in subjects over time (i.e., growing older, stronger, more tired or bored) (Kazdin, 1980). The subjects' process of change usually has to be given particular consideration in research experiments that last over a long period of time. However, this researcher is using the validity threat of maturation in a different context. The process of change and reaction may occur in patients and spouses who have been dealing with the cancer experience over a long period of time. Because of this, their responses may differ, for example, from a couple who has

just recently faced a cancer diagnosis. This situation is illustrated
by the husband and wife who both expressed (in an informal "chat" with
the researcher) that they had been dealing with the wife's cancer for
so long that they had said "all that there needed to be said." Whether
this was indicative of their general communication behavior, or simply
was a statement of fact, their response made this researcher realize
that the "stage" of the disease may have a great influence on the types
of responses that are made.

Instrumentation. This potential threat to validity refers to
"changes in the measuring instrument or measurement procedures over time"
(Kazdin, 1980, p.36). For this study, the researcher gave special
attention to the interview questions she asked, taking into account her
delivery and general nonverbal behavior during the interview session.
She also made herself become aware of the structure of the questions,
particularly the pre-chosen questions, in order to analyze how she
changed or adapted those questions to the conversational flow. The re-
searcher was also cognizant of standards and procedures she used to
analyze her data, for as Kazdin notes, "The standards that (the research-
ers) use in rating or observing behaviors may change over time" (p.36).
Using the constant comparative method and cross-checking with her adviser
and fellow judge throughout the research process helped to alleviate these
threats.

Bias. As McCall (in McCall and Simmons, 1969) discusses, every
qualitative researcher must question his or her role and its effect on
the subjects s/he is studying. The researcher must also address such
issues as his/her rapport with the respondents (too little? too much?),

and the syndrome that many qualitative experts describe and suggest to avoid--"going native." These are issues that fall under the heading of bias, and although bias is discussed under the section dealing with internal validity, it can also be a threat to external validity and to reliability.

A prevalent bias issue that this researcher dealt with in this study was that of "going native," or overidentifying with the subjects of the study. Schwartz and Jacobs (1975) further discuss this issue by saying that

> In some forms of participant observation the sociologist goes native in several senses of the word. He adapts an identity and a way of dealing with others that are normal, natural parts of some social-cultural world. Since he will not be a special kind of person, doing and thinking atypical things, his effect on this world, he hopes, will be minimized, (but), when the researcher is already familiar with and part of the scene he is studying, he need not worry about 'going native;' he is by definition already native-- that is, one of those he hopes to study (p.53).

Being a part of the world that one is studying has many advantages. The researcher can avoid the "gatekeepers" and get close to the pheno- menom being studied in a way that no other researcher can. Because s/he is part of the experience, his/her subjects will not act or react dif- ferently around the researcher. As a result, the researcher will not only be able to discern patterns of communication that seem to be oc- curring, but will also be able to understand how these patterns function for the communication participants.

However, "going native" can also have the disadvantage of having the researcher know too much about the phenomenom s/he is studying; the

researcher "takes so many things for granted that he no longer knows that he knows them" (Schwartz and Jacob, 1975, p.53). Because of this, the researcher may lose the distance and objectivity that is needed to see "scientifically" the "formal features or processes of the situation and how these relate to other social phenomena" (Schwartz and Jacobs, p.53).

Because this researcher has been a very active participant in the worlds of the hospital and patient, "going native" and its consequences were areas of important consideration for her. Her understanding and awareness of the "going native syndrome," along with the validity checks that will be discussed at the end of this section, helped to counteract this issue of bias, as well as the following and final bias issue to be discussed.

The other source of bias that may occur in this study deals with the nature of the research design itself. As Kazdin (1980, p.27) notes, "In most case reports, only anecodotal information is available about client (subject) behavior and therapeutic change." Reports that the respondents give in a case history type of research project such as this may tend to "be distorted and highly selective" (p.27-28).

Although this qualitative researcher "filtered" the data and did make conclusions or inferences about it, she did not necessarily accept the responses of her subjects as "truth." She instead considered the "importance of the first-person accounts in their own right, independent of(their) actual objective value" (Kazdin, 1980, p.27).

Internal validity checks. In order to counteract the preceding

"threats to internal validity," the researcher used the following internal validity checks:

1. The study used a convenience sample which included patients and spouses who were at different stages of their cancer. Finding patients who were newly diagnosed, in remission, or who had been dealing with the cancer for a period of time enabled the researcher to compare responses with descriptions of stages (an internal validity check for maturation and history threats).

2. The researcher cross-checked (when possible) questionable, interesting, and intriguing interview responses or behavior with family members, friends, or medical professionals involved with the respondents (a validity check for history and bias threats).

3. The researcher also used cross-check types of questions within the interview context itself. If, for example, the husband made a statement during the interview, the interviewer used a question with which to cross-check that response, not only with the wife, but later on with the husband to see if he still made the same response (a validity check for bias, researcher effect, and instrumentation).

4. The researcher used two types of interview formats--the couple together and then the couple apart (a validity cross-check for bias, instrumentation, history threats).

5. The researcher used the constant comparative method to analyze her past and present field notes to check whether the comparison results showed that she was exhibiting "going native" behavior.

6. The researcher also used the constant comparative method

throughout the research process as a validity check for all potential threats.

As McCall (in McCall and Simmons, 1969) posits, using multiple indicants and demanding a "very high degree of consonance among these indicants" can be the key to data quality control. This researcher's understanding of the potential threats to internal validity that this project may have, along with the internal validity checks and multiple methodological techniques she will be using within the research design, will help to alleviate problems in this area.

External Validity

"Internal validity addresses the initial question of whether a given experiment has demonstrated an unequivocally interpretable relationship. External validity addresses the larger question. Specifically, external validity refers to the extent to which the results of an experiment can be generalized" (Kazdin, 1980, p.42). External validity addresses the question that can be raised about the extent to which "the results can be extended to other populations, settings, measurement devices, experimenters, and so on" (p.42.). In order to ascertain whether this study's results have external validity or generalizability to other populations and/or people, the researcher, firstly, asked herself the following questions throughout the study's procedures: "Is this account consistent with other accounts of this event?", or "Have I assembled enough independent accounts of this event, and...compared among them for the degree of their agreement?" (Lofland, 1971, p.113). Secondly, in order to counteract the threats

to external validity, which will be discussed, the researcher compared her results and observations with the literature in the field of death, dying and communication, while also comparing her ongoing process and conclusions with other persons who were currently doing research in the same area.

Threats to External Validity

"Factors that may limit the generality of an experiment usually are not known until subsequent research expands upon the conditions under which the relationship (between the independent and dependent variables) was originally examined" (Kazdin, 1980, p.43). However, certain factors or characteristics were anticipated as being potential threats to this study's external validity.

Reactivity of outcome assessment. "Reactive assessment denotes that individuals are aware that their behavior is being assessed and may respond differently as a result" (Kazdin, p.43). An interview session with a tape recorder running may be viewed as an "artificial" situation for some respondents, even though they may, perhaps, be sitting in their own living room. In the two year participant observation experience, this researcher was able to alleviate this threat to external validity. Because she became a part of the world she was studying, people did not act or react differently because of her presence (as Sudnow would say, his continuous "hanging around" made people forget or simply accept his presence).

The interview sessions did not, however, allow for time to "hang around" and become part of the couple's world. As a result, the data

from the interview processes may have been influenced by the fact that the subjects knew they were being studied, what Kazdin refers to also as <u>reactivity to experimental arrangements</u> (p.45). The researcher tried to alleviate this threat by using her suggested validity checks, as well as by making her respondents feel as comfortable and unthreatened as possible. She used the constant comparative method to note differences in responses given during the taping of the interviews versus the friendly "chats" that took place before and after the interview sessions.

<u>Selection</u>. "This threat does not question the validity of the experimental finding but whether the finding would extend to subjects with characteristics other than those included in the investigations" (Kazdin, p.47). Although such factors as age, education or financial status did not separate this study's subjects from the general population, the fact that the couples were experiencing a life-threatening crisis did make them unique. However, this researcher believes that, firstly, if the literature in the field is accurate (and she believes it is), the responses and descriptions the subjects gave may generalize to other people facing the same type of crisis. And, secondly, the researcher believes that the responses that couples gave when discussing their cancer crisis may be extended to how people handle crises in general (again, noting what the literature in the field relates). One area of concern which the investigator had, though, was the differences that cultural backgrounds may bring to the handling of a cancer crisis (or any crisis). Because her availability sample yielded subjects who were generally not very different from each other as far as their nationalities,

no opportunity arose to explore how different nationalities deal with crisis situations (the researcher has an "intuitive hunch" that some cultural backgrounds allow and encourage more open displays of emotion or have different views of what death is).

Setting or situation. Another threat to external validity is that the finding "may be restricted to a particular setting or situation" (Kazdin, p.48). In her research process, the investigator anticipated differences in responses when interviewing a patient and spouse, for example, within the confines of a hospital room versus a living room. A particular setting may elicit a particular type of response, such as the situation which may arise where couples will tend to respond differently when each spouse is in the presence of the other versus being along with the interviewer. The researcher was aware of this possible threat and used the constant comparative method, as well as cross-checking types of interview questions to counteract the threat.

Combination of history and treatment. "The findings of an experiment are obtained at a particular point in time. For some findings it might be possible that the findings are not generalizable to another time in the past or future" (Kazdin, p.49). Although this threat was referred to indirectly in the maturation section (threats to internal validity), the researcher is aware that the physical stage of the disease and the reactive stages that the spouse and patient are experiencing will affect the generalizability of their responses. For example, a patient who is in a state of remission may forget or unconsciously repress how s/he acted or reacted when the cancer diagnosis was first made. The

interviewer, however, was able to explore the subjects' perceptions

and cross-check their responses within the interview context as well as

the participant observation context.

As Kazdin states:

> The fact that any of these factors (such as those just
> mentioned) are applicable to an investigation does not
> necessarily mean that external validity is jeopardized.
> If one of the above threats applies, it only means that
> some caution should be exercised in extending the results.
> The threat means that some special condition has been
> included in the experiment that may restrict generality.
> Only further investigation can attest to whether the
> potential threats to external validity of the results
> actually limit the generality of the findings (p.50).

This researcher would also like to add to Kazdin's statement that the

value of a finding may not always be determined by the degree of its

"generalizability." Her study may produce some results which are

important "precisely because their generality is very limited"(p.50).

The intimate and personal nature of the topic being researched attests

to this fact.

Conclusion. Watzlawick (1966) notes that the search for patterns

in communication phenomena is "the starting point of all scientific in-

vestigation" (p.136). The general framework and procedures of this

study, as well as the specific techniques and methodological cross-

checks it used to gather and analyze its data helped to aid this quali-

tative researcher in her attempts to discover communication patterns

and discern their function for those subjects whose lives she was

studying.

Chapter 3

PRESENTATION OF RESULTS

> We don't talk about it (his cancer); we don't dwell on
> it. We just go on as before--keeping busy, living a
> normal life. She doesn't break down in front of me
> and I don't fall apart when I'm with her. But, it's
> always in the back of our minds--always. Nighttime--
> that's the worst, that's when it really hits you....
>
> --male cancer patient

As was stated in chapter one, the purpose of this research is to
study "how communication patterns in a marital dyad are affected when
one of the members of that dyad has been diagnosed as having a life-
threatening illness." As was also noted in the communication section
of the literature review, very few studies in the past have dealt with
the area of communication during the crisis of a life-threatening illness,
particularly from the perspective of the family or marital system. A
systems view of the cancer experience promotes the perspective that a
patient's life-threatening illness and/or dying process is not only his
or her personal crisis, but the marital/familial system's crisis. The
ongoing, interactional communication process that occurs in disrupted
family systems reflects not only the general coping patterns that are
being used by those involved in the life-threatening crisis, but it also
reflects the general structure and functioning patterns of the family or
marital unit itself. Studying the communication patterns of families
facing loss or change, using a systems perspective, allowed this re-
searcher to explore three major areas of concern:

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1. What types of communication patterns are evidenced in married couples who are experiencing a life-threatening illness such as cancer?

2. How does the marital dyad respond to a life-threatening illness? How does the marital system adapt to and cope with the physical as well as psychosocial changes a life-threatening illness may precipitate?

3. How can I, as a researcher and as a caregiver, and others who work with the dying use the information obtained from this project to better understand and help those families of crisis who are facing possible loss or change?

The first two questions will be answered in this chapter. Question three will be addressed in chapter four, "Discussion of the Results."

The Respondents for the Study

Before presenting the results of this study, a brief discussion and description of the ten married couples will be given in order to set the stage for the results as well as to put the categorical data in the proper context.

Demographic data. Following is a table which gives the general demographic data about the ten couples who were interviewed during the study:

TABLE 3.1   DEMOGRAPHIC DATA: RESPONDENTS FOR THE STUDY

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1. Sex: 4 female patients; 6 male patients

2. Types of cancer:
   a. 2 patients with prostrate cancer
   b. 5 patients with lung cancer
   c. 1 patient with uterine cancer

d. 1 patient with breast cancer
e. 1 patient with an inoperable tumor of the brain/
   spinal cord (had not been diagnosed as cancer,
   yet was life-threatening)

3. Diagnosis time range: 2 months to 3 years

4. Personal data:
   a. ages (averages): wives--66, range: 36-69
                        husbands--67, range: 39-74
   b. years married: average: 31 years, range: 6-50 years
   c. times married: 8 couples married once
                      2 couples married twice
   d. children: 2 per couple (average), range: 1-6 children
                 average age of children: 38, range: 2-48
   e. occupations:
                 females: 7 homemakers, 1 parttime worker,
                           1 welfare worker, 1 retired nurse
                 males: 2 retired salesmen (1 was also the
                           manager of an agency), 1 retired rail-
                           roader, 1 manager of a state office
                           (in the process of retiring), 1
                           manager/owner of a small business,
                           1 laborer, 1 retired farmer, 1
                           teacher, 2 managers
   f. educational background:
                 females: 2--8th grade, 4 high school, 2 with
                           some college, 2 with college degrees
                 males: 5-high school, 2 with some college,
                           3 with college degrees
   g. nationalities: mixed (no prevalent trend)
   h. religious affiliation: 16 Protestant, 4 Catholic

The couples: A descriptive overview. Wilmot (1979) notes that

"As participants progress in a relationship, they work toward agree-

ment on the nature of their relationship" (p.152). He also discusses

that

1. relationships stabilize because the participants reach
   some minimal agreement (usually implicitly) on what
   they want from the relationship,

2. relationships can stabilize at differing levels of
   intimacy, and

3. a "stabilized" relationship still has areas of
   change occurring in it (p.152).

The researcher observed that, for the most part, the couples in-
terviewed for the study seemed to have reached some type of relational
stabilization or definitional agreement on what their relationship
should be. She felt this not only because of the average years (31)
that the couples had been married, but also because of the under-
standing and agreement their responses reflected about their personal
and dyadic roles and goals, as can be seen in the following sample
response, which illustrates the recurring type of metacommunicative
comments that were made about the nature of the couples' marriage
systems:

Husband: I think that something that both A and I
            wanted when we got married was a smooth
            relationship. Some people look for peaks
            and valleys; we wanted something a good
            deal smoother. Both of us were old enough
            to where we weren't looking for the peaks
            and valleys. I think we were both looking
            for a level type of relationship and a rather
            relatively stable type of marriage.

Most dyadic partners seemed to have well-defined role functions
which enabled them to work together for the common goals of the marriage.
The researcher also observed that the relational stabilization that had
been achieved in eight of the ten couples could be described as "tradition-
al" type of definitional agreement (Fitzpatrick, 1977) in that the couples
seem to

        follow a fairly customary belief in the marital relation-
        ship. They prefer little autonomy from one another and
        impose few limitations on the other's use of physical

and emotional space. They have a high degree of
sharing with one another and tend to engage in rather
than avoid conflict....They are highly interdependent
and are opposed to the idealogy of uncertainty and
change (Wilmot, 1979, p.153).

Throughout the years the marriage participants report that they have

had their "ups and downs" and all observe that they have had their

share of problems, whether financial, social, emotional or personal

in nature, but as one female spouse reports:

...We've been able to kind of fight through the
things that married couples often do have to go
through. I really do feel that people that do have
to struggle and work at building relationships have
stronger relationships. I think that anything you
do together helps to build that relationship. If you
never have hobbies that are the same or share the
same type of interests, I think it would be very,
very difficult.

Her response exemplifies much of what the other couples reported about

their lives together. Collaboration, sharing, acceptance of differences,

support and control seemed to characterize most of the marital systems

involved. Control whether it concerned emotions or role boundaries

(i.e. "I am the patriarch, the umbrella for the family; my wife is the

communication link with the children."), was determined by the researcher

to be a key contributing factor to the functioning of many of the marital

systems. The male participants in the study, in particular, reported

that keeping their emotions under control and their role labels stabilized

was very important and necessary in order for them to cope not only with

the cancer experience but also with their everyday lives. Female

respondents, on the other hand, exhibited, as well as reported, that they felt freer to express their inner feelings as well as to make homeostatic changes without undue personal discomfort or conflict.

Besides the stereotypical differences that were noted in the interviewees' responses, the age and stage of life that the patients and spouses were experiencing must also be considered when analyzing the data that their responses elicited.

Life cycle. The positions in the life cycle continuum of these couples adds to an understanding of the context of their responses. Brody (1977) notes that how well the family copes with a life-threatening illness depends not only on the prospects for recovery, the initial strength of the family unit and how the members are able to function within that unit, but also on the circumstances and age of the patient.

> A diagnosis of cancer in a husband creates problems for the 70-year-old woman with married children which are vastly different from those problems of a 35-year-old mother of three youngsters. Sometimes cancer disrupts typical family roles, such as who earns the income and who cares for the household, necessitating a host of psychological and physical adjustments (Brody, 1977, p.196).

In his formulation of the eight stages of ego development, Erickson (1959) theorizes that each stage (infancy to old age) is characterized by a central conflict. The resolution of the conflict determines the individual's future development, his success in adapting to internal and external demands, and his self-evaluation.

For all but one of the study's couples, the life cycle stage can be described as either the "middle years" or the "older years." Blumberg et al. (1980) note that for the couple experiencing the middle years,

middle age can make heavy demands on an individual's stability and

adaptability:

> The "empty nest" which occurs when children have grown and
> begun their own lives, the death of parents and the death
> of peers are enormous changes. Successful adaptation requires
> emotional reinvestment in people or activities outside the
> family or sphere of close friends...If an individual cannot
> establish alternative relationships or pursuits, a sense of
> loss, of life passing one by, may be magnified out of pro-
> portion to reality, creating a sense of isolation that cancer
> can only compound (p.9).

Every couple in the study reported that they had been touched in

some way by death (in many cases from cancer). The loss of a parent,

friend, or family member (distant or close) made many of the interviewees

report that they had a new strength, new attitude, different reaction

or a new fear/horror concerning the possibility of the outcome of their

own or their spouse's illness. As one female patient reported, "All of

these deaths (family/friends), they've just come too close, too close.

It makes you uncomfortable."

For all but one couple the "empty nest" syndrome was a reality, with

most children having left home (or in the process of leaving home) in

order to get married, pursue a career or go to school. Responses con-

cerning the children and the "empty places at the table" ranged from

sadness ("It just hasn't been the same since the last one left.") to

relief ("We were getting along so badly that I am glad he is gone.").

Whether the parting was happy or sad, having the children leave home

made a notable difference in the couples' lives. And, as Erickson

discussed, many of the couples reported that they tried to invest

their newly-found time and energy in each other, in outside activities

or in their work.

For the older person, coming to terms with the aging process and all the changes it precipitates is the developmental task that she or he must face. As Pattison (1977) states, "It would appear that the elderly must resolve the issue of meaning in their lives as they approach death..." (p.277). Erickson (1963) notes that the older person's task is to develop "ego-integrity," that is, a basic acceptance of one's life as having been inevitable, appropriate and meaningful. One should have contentment with one's life as opposed to despair.

Retirement can represent a significant threat to the achievement of this contentment for there is the inevitable loss of the role of"bread-winner" or "wage earner." The end of this role function may also precipitate drastic changes in homeostatic lifestyle patterns and routines. For some, retirement may represent an end; for others it can represent a new and meaningful beginning. Combining the aging process and all the physical, psychological and social changes it causes, along with the physical and psychosocial changes that may occur with the advent of a life-threatening illness such as cancer can create the potential for a very difficult situation which will force the parties involved to use every adaptive skill and response possible in order to cope.

The couples who reported that they had been or were in the process of dealing with the retirement issue and the changes that ensued, discussed many different ways in which they were dealing with the new lifestyle that had been dictated for them. For the most part, couples related that they were doing more things together such as shopping, fixing up

the house, camping or taking trips. Many reported that the adjustment
of having the husband home was difficult, with the wives observing that
they were usually the ones who had to make the definitive changes in
their lifestyles to suit their husbands' needs (i.e., "I found myself
spending more time doing what my husband wanted us to do that I did
doing what I wanted to do."; "I used to be able to go have lunch or go
swimming, but with N home, that came to a screeching halt."). Many
couples reported that the retirement experience enabled them to be
better prepared for the cancer experience in that it helped them deal
with the husband being home and the empty hours to fill. Many couples,
after initially losing their equilibrium due to the husband's retire-
ment, recovered their homeostatic balance. Because of this pre-illness
experience, the onslaught of cancer was not as shocking or disruptive
as it could have been for some of these marital systems because, as they
reported, they had learned to become more adaptive to the changes that
the aging process precipitates.

The middle aged or older couples observed that there were advantages
to being where they were in the life cycle, particularly when it came to
dealing with their life-threatening crises. Many reported that upon
hearing the diagnosis of cancer they had an initial reaction of being
relieved that their children were raised and able to take care of them-
selves. From the young couple which was interviewed there was no such
response. For them the issues of the future, the children, making a
living and finances were the main concerns. As the wife said,

...I don't know what to think. I know I'll have to get a

job, but who will take care of my husband and kids? He
can't take care of himself and I don't want to leave him
alone with them. He might have an attack and what would
happen to them? They're too young to take care of them-
selves. If he should die...what will happen to me? To
our house? What do I do--declare bankruptcy?"

These are not issues that the older couple usually has to deal with.

The child-raising, job hunting and maintaining, and the house buying and

mortgaging processes have usually been completed. What they do have to

contend with is their feelings about those completions and the emptiness

that may result if such factors were the only things that gave their

lives meaning and purpose.

Cancer at any age is devastating and disruptive, but each stage of

the life cycle brings its own unique problems and frustrations to the

cancer experience. Knowing the general context of the responses and

background of these couples may diminish confusion and answer some

questions which may arise about the respondents and the small portraits

of life that their responses painted.

The Inductive Process

As was discussed in chapter two, the inductive process of this

qualitative research was implemented by using interviewing and partici-

pant and nonparticipant observational methodologies. In her search

for information about the dyadic partners' communication systems

and processes, the use of the qualitative techniques just mentioned

above better enabled the researcher to inductively understand, interpret

and conceptualize different communication patterns and their meaning

and function for the marital partners and for others involved in their

cancer experience (Bruyn, in Filstead, 1970).

After interviewing, coding, and transcribing of the tapes, the researcher initially grouped cards into 42 different categories, from which she combined or collapsed, regrouped or delineated categories, resulting in the three major categories and fifteen descriptive subcategories which follow.   These categories were then given to Judge A to be inductively tested. Categories are described in abbreviated form due to their length, but will be described fully later in this chapter.

TABLE 3.2   OUTLINE OF INITIAL PATTERN CODING

I. How the marital dyad is incorporated into the medical world
   I1. Rules for initial diagnosis
   I2. Rule for type of language used by doctor
   I3. Rules for the doctor and hospital personnel to maintain control
   I4. Rules that the hospital personnel follow in talking about the illness with the patient and spouse

II. The marital system's initial response to being incorporated into the medical world
   II1. Loss of control
   II2. Fear of alienation/isolation/unacceptability

III. How the marital system adapts to being assimilated into the medical world
   III1. The dyadic partners become information seekers and processors
   III2. One of the partners assigns or is assigned the role of communication link with the doctor and conveyer and filterer of information for the other spouse
   III3. Partners communicate about the illness on a content level

III4.   The couple seeks to find and/or assign a meaning
          or purpose to the illness
III5.   The couple collaborates in the denial process
          in some way (negating/minimizing/avoiding/
          suppressing)
III5b.   If suppression is not collaborative, one or the
          other spouse may seek communication links with
          sources outside the marital system or may non-
          verbally express his/her feelings within the
          system
III6.   The system seeks/receives support from within
          and outside of the marital system
III7.   The dyadic couple uses humor to achieve some
          level of detachment from the cancer experience
III8.   Entry into the medical system may precipitate
          new topics of discussion

_____

Judge A's Inductive Testing: Process and Results

Judge A was given 143 cards which were randomly picked (as explained

in chapter two) from the 15 subcategories and was given the following

instructions:

1. Sort the cards into not fewer than 12 and not more than
     18 new categories

2. Allow no more than 10% of the cards in an uncategorized
     ("I don't know") group

3. Look at the properties of the categories and write rich
     descriptive sentences about your newly-formed categories

4. Use a systems perspective to clarify the categories

5. Do not turn the cards over (card had original code
     on back)

Following (Table 3.3) is a tabulated overview of Judge A's categori-

cal generation.   The inductive testing process, as reported by Judge A,

took from ten to twelve hours over two day period.

Explanation of Table 3.3. For an understanding of Table 3.3's

content and meaning, the figures in the table should be viewed as steps

in a process (the inductive processes of the researcher and Judge A)

that starts at the left of the table (column one) and ends at the right

of the table (column six). For example, in focusing on the first column

in the table, the figures "I_1" and "I_2" are the numerical names of the

researcher's first two categories--"Rules for Communicating the Diagnosis"

and "Rule for the Type of Language Used By the Doctor." The table shows

that in the "I_1" category, the researcher had ten cards, and in her "I_2"

category, she had six cards.

When Judge A received the randomized cards, she sorted the cards

and created category "1" (Doctor/Patient Relationship). In this category

she put all of the researcher I_1 and I_2 cards ($10-I_1$, $6-I_2$); because

her category description so closely matched that of the researcher's

original I_1 and I_2 categories, the researcher collapsed her first two

categories, as is noted on the table. The last two columns thus show

how many of the cards in Judge A's new category description matched

the researcher's original card descriptions and the resulting percentage

of judge/researcher reliability.

TABLE 3.3 TABULATED RESULTS: JUDGE A/RESEARCHER CORRELATION

A Researcher		Judge A			
Category/Code	# of Cards	Category/Code	# of Cards/Codes	Match	%
I_1	10	1	$16 \begin{array}{l}10\text{-}I_1 \\ 6\text{-}I_2\end{array}$	10	100%
I_2	6	(Judge A Collapsed I_1 - I_2 categories)			
I_3	10	2	$6 \begin{array}{l}5\text{-}I_3 \\ 1\text{-}II_1\end{array}$	5	50%
I_4	10	3	$9 \ \text{-}I_4$	9	70%
II_1	10	4	$5 \ 5\text{-}II_1$	5	70%
		5	$5 \begin{array}{l}2\text{-}II_1 \\ 3\text{-}I_3\end{array}$	2	
		(Judge A's categories(#4&#5)both matched category II_1)			
II_2	10	6	$10 \begin{array}{l}9\text{-}II_2 \\ 1\text{-}I_3\end{array}$	9	90%
III_1	10	7	$9 \begin{array}{l}7\text{-}III_1 \\ 1\text{-}III_6 \\ 1\text{-}I_4\end{array}$	7	70%
III_2	10	8	$10 \begin{array}{l}9\text{-}III_2 \\ 1\text{-}III_1\end{array}$	9	90%
III_3	10	9	$8 \begin{array}{l}5\text{-}III_3 \\ 1\text{-}III_2 \\ 1\text{-}III_{5b} \\ 1\text{-}III_6\end{array}$	5	50%
III_4	10	10	$6 \begin{array}{l}4\text{-}III_4 \\ 2\text{-}III_6\end{array}$	4	40%
			$5 \ 5\text{-}III_4$	5	50%
III_5	10	12	$12 \begin{array}{l}10\text{-}III_5 \\ 1\text{-}III_3 \\ 1\text{-}III_{5b}\end{array}$	10	100%
III_{5b}	10	13	$8 \begin{array}{l}7\text{-}III_{5b} \\ 1\text{-}III_3\end{array}$	7	70%

TABLE 3.3 continued

A - Researcher		Judge A			
Category/Code	# of Cards	Category/Code	# of Cards/Codes	Match	%
III_6	10	14	5 5-III_6	5	50%
III_7	7	15	7 III_7	7	100%
III_8	10	16	10 III_8	10	100%
			12 uncategorized		
			___(Less than 10%)		
	N =143		N=143		

Judge A similarly matched 115/143 cards with the researcher's original categories, resulting in 84% reliability with the researcher. Following (Table 3.4) is the index/summary table for the in-depth analysis of Judge A's categorization scheme and descriptions, shown in Table 3.5. Table 3.5 is set up not only to show how Judge A's categories correspond with the researcher's categories, but also to show the changes made in reflecting Judge A's inductive process and input.

For instance, in the judge/researcher correlation shown in category 2, p.151, the researcher concluded, because of Judge A's input, that one of the contributing factors to the marital system's initial response of loss of control was that the doctor or hospital personnel maintained control over the couple. Consequently the researcher collapsed her I_3 category with her II_1 category and decided to expand the resulting

description to include the "demi-god" aspect of the doctor, feeling that

it gave insight and understanding to the complete picture of why a patient

and spouse may experience a sense of "lost control" after having a cancer

diagnosis. In discussing the aspect of the doctor's "God" image (after

the inductive testing was over), the researcher and Judge A also con-

cluded that some of the patients and spouses were voluntarily giving up

their control to the doctor, giving him or her the responsibility for the

illness. Because of this, the researcher further expanded the category

description to include this observation.

TABLE 3.4 SUMMARY OF RESEARCHER/JUDGE A CORRELATION

Judge A's Category	Researcher's Category	Resulting Category
"Doctor/Patient Relationship"	"Communicating the Diagnosis" "Language Used During Diagnosis"	"Communicating the Diagnosis"
"Doctor/Patient Relationship: Control by Professional"	"Physician As Controller: "Initial Response: Loss of Control"	"Initial Response: Loss of Control"
"Staff/Patient Relationship:	Staff: Content level Communication With Patient"	"Talking About The Illness"
"Loss of Control Caused By the Disease"	"Physician As Controller" "Initial Response: Loss of Control"	"Initial Response: Loss of Control"
"Cancer Changes the Life-style of the System"	"Initial Response: Loss of Control"	"Initial Response: Loss of Control"
"Isolation: The Leper Stage"	"Initial Response: Fear of Alienation and Un-acceptability"	"Fear of Alienation/ Isolation"

TABLE 3.4 continued

Judge A's Category	Researcher's Category	Resulting Category
"Information As A Coping Mechanism"	"The Dyadic Partners: Information Seekers and Processors"	"Information Processing"
"Information Givers"	"Dyadic Partner As Communication Link" "The Dyadic Partners: Information Seekers and Processors"	"Information Processing"
"Denial: Things Will Be All Right"	"Content Level Communicating By Dyadic Partners"	"The Denial Process" "Suppression" "Content Level Communicating"
"Finding Meaning: 'Why Me?'"	"Finding A Purpose Or Meaning"	"Finding A Purpose Or Meaning"
"Acceptance of Mortality, Meaning Of Life"	"Finding A Purpose Or Meaning"	"Finding A Purpose Or Meaning"
"Beginning Of Acceptance"	"Denial Process"	"The Denial Process"
"Coping With The Disease Before The System Accepts It"	"If Suppression Is Not Collaborative"	"If Suppression Is Not Collaborative"
"Coping Mechanisms: Support and Caring From Friends"	"The System Seeks and Receives Support"	"The Familial and Social Systems Respond With Support"
"Coping Mechanism: Sense of Humor"	"Sense of Humor"	"Coping By Using Humor"
"System's Acceptance Of The Disease"	"Illness Precipitates New Communication Channels"	"Illness Precipitates New Communication Channels"

TABLE 3.5 JUDGE A'S INDUCTIVE CATEGORIES/RESEARCHER'S
CORRESPONDING CATEGORIES

Category 1. "Doctor/Patient Relationship (10-I1, 6-I2)
Judge's
Description: Contact with medical professional (chief givers of
information). How the professionals talk to the family unit: It
is important to the patients that communication with professionals
be clear, straightforward, honest. Clear--understandable, no jargon.
Language needs to be clear and simple. Straightforward--the people need
to feel free to ask questions. Honest--Patients want the news straight,
no promises of cures. Level with the patients--success rates, etc.

Researcher's Corresponding Category Descriptions:
    Category I1: When communicating the initial diagnosis, the doctor
should convey an honest, positive, yet rational view of the cancer
diagnosis. S/he should concentrate on the positive aspects of the
disease and treatment plan without creating false hope or illusion of
immediate cure.

    Category I2: When communicating with the patient/spouse, the doctor
should use a communication level which is understandable to the couple so
they can better understand and adapt to the new information and/or rules
conveyed in the initial diagnosis.

Changes: Researcher collapsed category I2 with category I1.

Category 2. Doctor/Patient Relationship: Control by Professional
            (5-I3, 1-II1)

Judge's
Description: Patients feel as if they have no choice in control over
decisions concerning the cancer. Almost as if some doctors were viewed as
"demi-gods" who people were afraid to question or confront. Doctors
appeared to take taken charge of person's choice--as if the patient was
now "territory" of the doctor.

Researcher's Corresponding Category Descriptions:
    Category I3: In incorporating the subsystem into the larger medical
community, the doctor and/or medical profession maintain their homeo-
static roles of "decision-makers" or "controllers." The spouse and patient
have to adapt to the medical community's rules.

Category II₁: As an initial response to being incorporated into
the medical system, the couple feels a loss of control due to(1) the
nature of the illness, its implications and treatment, and(2) being in
the medical world. The couple also experiences feelings of helpless-
ness over their loss of homeostatic role functions and lifestyle patterns.

Changes: Researcher collapsed her I3 category with her II1 cate-
gory and included the "demi-god" aspect in the description.

Category 3. Staff/Patient Relationship (9-I4)
Judge's
Description: Denial of cancer by general staff at hospital, or were
they treating cancer as just another illness? Patients report that the
medical staff tended not to discuss "cancer." The word cancer was avoided
as were the feelings and one's coping with the disease.

Researcher's Corresponding Category:
I4: In order to preserve personal boundaries and in order to main-
tain emotional and interactional stability, the medical staff and/or
hospital personnel communicate with the patient/spouse subsystem on a
content level. The meaning of the illness is defined and conveyed through
the physical care of the patient. All verbal communication about or
mentioning of the word cancer is avoided.

Changes: Researcher made no changes in her category description,
but did use the aspect of "denial of cancer" (by the hospital staff) in
her discussion of the "denial" process (chapter 4).

Category 4. Loss of control by the disease. (3-I3, 2-II1)
Judge's
Description: This stage--angry and fighting or full of despair--
giving up. Person's activities and choices restructured because of
physical problems from disease.

Researcher's Corresponding Categories:
I3.: In incorporating the subsystem into the larger medical community,
the doctor and/or medical profession maintain their homeostatic roles of
"decision-makers" or "controllers." The spouse and patient has to adapt
to the medical community's rules.

II1.: As a response to being incorporated into the medical system,
the couple feels loss of control due(1) the nature of the illness, its
implications and treatment and(2)the medical world. They have feelings
of helplessness over their loss of homeostatic roles and lifestyle patterns.

Changes: Categories were collapsed (see category 2)

Category 5. Cancer changing the lifestyle of the system--the system's reactions to this (5-II1)
Judge's
Description: Members report a reduction in their activities. Affects their roles in the system. System has to cope with outside complications of cancer--drugs, financial problems.

Researcher's Corresponding Category:
II1-see page 151, category 2.

Changes: None

Category 6. Isolation: The "leper" stage (9-II2, 1-I3)
Judge's
Description: Cancer viewed as a contagious disease--infecting offspring, spouse, friends. Person feels like a leper, an outcast, withdraws from the world. People don't talk about the cancer; friends go away.

Researcher's Corresponding Categories:
II2: Responses, fears and concerns that the marital system feels in being incorporated into the medical world include the fear of alienation from others due to fears of unacceptability and isolation due to the nature of cancer ("dirty," "contagious") and due to the social death syndrome (loss of social identity, self-worth, characteristic of being "alive").

I3: see page 152, category 4.

Changes: Researcher expanded category to include "leper" description.

Category 7. Information as a Coping Mechanism (7-II1, 1-III6, 1-I4)
Judge's
Description: The system seeks information to make sense out of the disease. The wisdom of professionals outside of the medical staff (who diagnose and treat) is sought. The period consists of a "checking out." Did I hear the doctor correctly? What do you think this means? Often the patient hears only the advice of the secondary source.

Researcher's Corresponding Categories:
III1: The dyadic partners become information seekers and processors in order to learn the rules of the medical community. They seek credible information sources and ask questions.

II6: The marital dyad seeks and/or receives support both from within its marital system and from outside of the system--in the family and social

systems, in order to maintain emotional stability and relational identity which were both affected by its being incorporated into the medical world.

I4:   see page 152, category 3.

Changes: Researcher dropped the word <u>seekers</u>.   See next category discussion for full analysis of changes.

Category 8.   "Information Givers" (9-II2, 1-III1)
Judge's
Description: Information is conveyed through a trusted third party(1) when they did not hear what the doctor was saying or(2) someone with similar experiences is listened to--confirm feelings/reactions are normal.   Intensity of the news is lessened when heard through a trusted non-professional.   Person without cancer can be more objective.

Researcher's Corresponding Categories:
III2:   One of the partners assigns him/herself, or is assigned the role of communication link with the doctor and information conveyer and filterer for the other spouse.

III1:   The dyadic partners become information seekers and processors in order to learn the rules of the medical community.

Changes: Researcher collapsed category III2 with III1.   She dropped section on "to learn the rules..." and included the aspect of "Intensity of the news is lessened...."   Researcher also expanded category to include the concept of "intellectual mastery over the disease."

Category 9.   Denial: "Things will be all right." (5-III3, 1-III2, 1-III5b, 1-III6)
Judge's
Description: Action takes precedence.   Members talk more about positive aspects, i.e. the percentage rate of success.   Selective "hearing"--patient tries to ignore the negative aspects.   Feelings and outcome are avoided.

Researcher's Corresponding Categories:
III3:   Partners work out ways of communicating their feelings by letting the content level of communication carry the emotional/relational meaning of the illness and by finding appropriate situations where they can communicate.

III2:   One of the partners assigns or is assigned the role of communication link with the doctor....

III5b: If suppression is not collaborative, that is, if only one of the marital system's members is avoiding/suppressing about the subject of cancer, the other spouse may seek communication links with sources outside of the dyad.

III6:   The dyad seek and receives support from within and outside of the marital system....

Changes: Researcher decided to make a separate category for "suppression," deciding that the evidence was strong enough for it to have its own category.

Category 10.   Finding Meaning--"Why Me?" (4-III4, 2-III6)
Judge's
Description: The cards are stacked.   It was determined by outside forces--being chosen by God gives strength.   Responsibility shifted to outside force.   Not necessary to understand.

Researcher's Corresponding Categories:
III4:   The couple searches to find and/or assign a meaning or purpose to the illness in order to incorporate it into their marital system's functioning patterns.

III6:   The marital system seeks and receives support....

Changes: Researcher delineated a new category from the meaning category which specifically dealt with religion/faith/religious beliefs.

Category 11.   Acceptance of Mortality (Meaning of Life) (5-III4)
Judge's
Description: --system operates in the "here and now" (All we have is today.)   Priorities change--life not taken for granted.   People are most important.   "The Wisdom Stage" --system has come to terms with death. The juxtaposition of life and death has resulted in new meaning.   The "Thanksgiving and Goodbye" stage.   Person realizes the importance of life and yet is willing to let go.

Researcher's Corresponding Categories:
III4:   The couple seeks to find and/or assign a meaning or purpose to the illness.

Changes: Researcher left her original category as it was but did use Judge A's input for general discussion of the category.

Category 12.   Beginning of Acceptance (10-III5, 1-III3, 1-III5b)
Judge's
Description: Feelings--nonverbally expressed (tears). Couple is
beginning to discuss treatments; cancer "leaking" into consciousness,
but pushed away. Patients don't dwell on the topic. High hopes for cure.

Researcher's Corresponding Categories:
III5:   The couple collaborates in the denial process at some level:
(1) denial concerning the diagnosis and/or facts of the disease;(2) denial
concerning the disease and its implications/extensions, and(3) denial
of extinction. "Denial" can be communicated by negating, minimizing or
by talking only positively (which creates an illusion that everything is
"all right"). The couple may also suppress or avoid the subject of cancer
completely.

III3:   Couple discusses the illness on content rather than a feeling
level....

III5b: If suppression is not a collaborative effort, spouse may
seek outside communication links....

Changes: Researcher delineated a new category from the denial cate-
gory, with the topic of suppression being given its own category (as
discussed in category 9).

Category 13.   Coping with the disease before the system accepts it.
(7-III5b, 1-III3)
Judge's
Description: When one member of the system refuses to talk about
or is denying the disease, the other member will vent concerns with out-
side members. This reduces tension within the system. There has to be
a release for the pressure.

Researcher's Corresponding Categories:
III5b: see preceding category (If suppression is not a collaborative
effort....)

III3:   see preceding category

Changes: Researcher included aspect of "releasing tension" outside
of the marital system in order to maintain homeostasis within the system.

Category 14.   Coping Mechanisms: Support and Caring From Friends
(5-III6)

Judge's Description: Patients need to know that friends care and are concerned and willing to support the patient by giving their time and presence. This support informs the patient that the sickness need not isolate them--lets patient know that "You are OK!" People care enough to make adjustments. Patient needs to talk about feelings.

Researcher's Corresponding Category:
III6: System seeks and receives support from within the system and outside of system....

Changes: Researcher dropped the word <u>seek</u> (already discussed).

Category 15. Coping Mechanism: Sense of Humor (7-III7)
Judge's
Description: Patients are coping with the uncertainty. Humor reduces the stress and tension caused by the uncertainty. "Laughing in the face of danger" (I can handle this problem.)

Researcher's Corresponding Category:
III7: The dyadic partners use humor to achieve some level of detachment from the cancer experience and the medical community.

Changes: The researcher combined Judge A's description with her own.

Category 16. System's Acceptance of the Disease (10-III8)
Judge's
Description: System is beginning to cope with the disease realistically--sharing feeling. "Pragmatic" stage--what we have to do. Actions are taken to compensate for the disease, i.e. paying bills, preparing for death. Members are now able to speak about the illness and its effect on their lives. Communication becomes more open concerning cancer and other issues. Also, offspring now are beginning to share in this communication. It is easier to talk about the cancer.

Researcher's Corresponding Category:
III8: Entry into the medical system may precipitate new topics of discussion within the marital dyad.

Changes: Researcher combined Judge A's description with her own.

Additional Comments On Judge A's Inductive Process and Results

Judge A's categorical descriptions reflected an overall "stage" approach to the responses. Such descriptions as the "the Acceptance Stage," the "Wisdom Stage" and the "Thanksgiving and Goodbye Stage" are reminiscent of Kubler-Ross's five stages of reactions to possible loss or death (with which Judge A reports she was familiar). Although in several instances the researcher used Judge A's "staging" titles to enhance her own original categorical descriptions, for the most part, she felt that the stage idea was already inherent in her description.

The researcher was gratified that the high percentage of judge/ researcher correspondence concerning categorical results validated her initial impressions. She was also impressed with how Judge A's categories enhanced her own. As the researcher later told Judge A, "It's like I built the house and you decorated it." As can be concluded from analyzing Table 3.5, rarely does it occur that there are questions, confusion or conflicts as to why Judge A categorized or described as she did. Furthermore, if the researcher did not directly incorporate Judge A's descriptions into her own categories, she used them in her discussion of the categories (see chapter four). Thus, the inductive process of Judge A proved to be not only an excellent reliability check for the researcher's findings, but also an important step in adding substance and description to the researcher's original categories.

Judge B's Deductive Testing: Process and Results

Judge B was given 137 randomly selected cards as well as the categorical title descriptions and was told to file the cards into the (now)

fifteen predetermined descriptive categories, as she saw fit. She was

told to place the "response" cards into the categories which best described

the type of communication pattern or interaction that the card's response

reflected. Following (Table 3.6) are the tabulated results of Judge B's

deductive process. Her judging took approximately six hours and was done

in the presence of the researcher. She, like Judge A, was told not to

turn the cards over, which would have revealed the original code of the

card.

TABLE 3.6   JUDGE B'S DEDUCTIVE TESTING RESULTS

| | Researcher | Judge B | | |
Category/Code	# of Cards in Category	# of Cards	# of Matching	%
I1	10	10	10	100%
I2	10	10	10	100%
II1	10	10	9	90%
II2	10	10	8	80%
III1	10	10	10	100%
III2	10	10	9	90%
III2b	10	10	9	90%
III3	10	7	7	70%
III3b	10	8	3	30%
III3c	10	11	8	80%
III3d	10	9	6	60%
III3e	7	7	7	100%
III4	10	12	9	90%
III5	10	13	9	90%
	N = 137	N = 137	N = 114	83% (average)

Judge B matched 114/137 cards, resulting in 83% reliability with the previous two judges (researcher and Judge A). Judge B's deductive testing and consequential comments about the categories and the grouping process also resulted in some further changes and enhancements of the category descriptions:

1. Because of the low percentage (30%) of matching in the "content vs. feeling" category (III3b), the researcher and adviser developed a new, more descriptive explanation of the category. Because Judge B expressed her confusion over what "content" means, the category was described as "The couple metacommunicates about how they handle their feelings--by collaborating in a "Let's Pretend Everything Is All Right" game. This seemed to be a more accurate description of the properties of the cards filed in this category.

2. Judge B discussed the need for the researcher to define/describe what support meant in Category III4, which the researcher did (confirmation/ affirmation). After looking at the cards and discussing the category with Judge B, the researcher also decided to drop the "seeking" perspective of support (The marital couple seeks support) and use only the receiving aspect of the support process (i.e., the family/social systems respond and give affirmation/confirmation).

3. Judge B reported that she was confused about what "mixed messages" were (Category III5), relating that she found herself looking for "mixed messages in everything." For her final category, the researcher specified what "mixed-messages" are.

4. The researcher and judge discussed but came to no resolution

concerning the judge's frustration over how to view a response card--

literally, metaphorically, relationally, etc. As Judge B noted, she had

to take the properties of the cards at "face value" because she did not

know what the relationship of the people involved was like and she

worried (as Judge A did) all the way through the testing process that,

as she reported, she would be "out in left field." However, her results

and high percentage of reliability proved that her concerns were unfounded

for purposes of this study.

The Categorical Results

Following are the specific categorical results which this quali-

tative study has yielded. The researcher has delineated three major

categories or stages of the cancer experience: (1) the discovery and

confirmation of the diagnosis of cancer; (2) the initial reaction of

the patient and spouse system; and (3) the further coping responses

of the marital dyad. Under these three major areas of concern are

descriptive subcategories which reflect the communication process

and patterns that are occurring. For the purpose of this study, a

"category" determination is constituted by similar responses from at

least six different couples or eleven individuals.

The Discovery and Confirmation of a Cancer Diagnosis (Major Category

1). How the medical community incorporates the marital system into its

larger system.

In this major category of responses, the interviewees reported in-

formation and described behavior from which the researcher identified

certain communication patterns and processes that seemed to be operating

in the medical establishment/marital dyad system. The patterns describe

how diagnoses are communicated as well as how the cancer is talked about

within the medical world.

> Communicating the Diagnosis (Pattern I.) When communicating
> the initial diagnosis, the doctor should be clear, under-
> standable, straightforward and honest, presenting a "rational"
> view of the situation/disease and treatment plan, without
> creating false hope or illusion of immediate cure. The
> doctor should not confirm a cancer diagnosis until abso-
> lutely certain of the diagnosis, but the doctor may fore-
> warn the patient and spouse that a cancer diagnosis is
> a possibility in order to prepare them for the forth-
> coming news.

Bard (1970) notes that the cancer experience can be viewed as a

sequence of related events proceeding from the first perception of a

sign of illness, to hospitalization and treatment, and then to convales-

cence and cure, or to recurrence and death. "Diagnosis is the first

intervention point in that sequence. The manner of communicating the

diagnosis and the subsequent reactions of patient and family establish

a pattern of coping and adaptation that continues throughout the disease"

(Blumberg et al., 1980, p.11).

Although in years past, as was noted in chapter one, medical doctors,

as a practice, did not always tell their patients the complete story about

having cancer, the subjects of this study reported that their doctors were

quite open and honest about the cancer diagnosis, a reversal in the trend

of withholding information which recent studies in the field support

(Novack et al., 1979; Holland, 1976). And, as McIntosh (1974) reports,

"Patients prefer being told rather than being kept in ignorance" (p.167),

an observation which the interviewees' responses supported:

male patient:	I think that he (the doctor) practices good medicine. He said, 'Yes, you have a cancer. It's a disease that happens to our age group.' He was trying to make me feel better.
male spouse:	I think, though, that my wife and I both agree that we appreciate the doctor coming right out and telling us instead of beating around the bush....
female patient:	I'd much rather know the truth no matter how bad it is. I think you have a right to know....It's your body and you go through it.
male patient:	I liked Dr. K. He explained everything and he didn't pull any punches, which I admire because if there's something wrong, I want to know. I don't want them to kid me along because a guy has to make a few arrangements if he's only got so long to live.

Besides being open and honest, the doctors (as reported by the patients and spouses) presented a "rational view" of the cancer--concentrating on the positive aspects, yet not creating false hope. Blumberg et al. (1980) note that "The question in conveying the diagnosis is not one of distorting the truth, but of determining what truthful aspects of the situation will be most useful and least harmful to the

patient" (p.14).

Reflecting a rational or realistic view of the cancer during the initial diagnosis may be a process that is complex and difficult for the doctor, particularly if s/he is not knowledgeable about the family or patient's state of mind or general coping styles. The doctor's own medical training and personal feelings about cancer and death may also contribute to the manner in which the diagnosis is communicated, as well as to the type of positive or negative attitude projected about the prospects for recovery. From the following sample responses, it can be inferred that many doctors opt for a "middle of the road" type of outlook, balancing the positive and negative aspects of the disease:

female patient:	(The doctor's communication) was a very positive type of communication. Yet, never anywhere along the line did they use the word cure.
husband (patient):	The doctors don't talk "cure"; they talk remission--which the doc describes as 'killing it so it don't come back.'
wife:	They don't like to use the word (cured) because they don't know.
husband:	They say they can put it into remission, but it can start up someplace else.
female patient:	The doctor was right to the point, I had cancer, I should take chemo and radiation, but there

was much to be hopeful for....

male patient: Waiting for the results was most difficult,

but I did appreciate the doctor's communication.

He was not overly-confident, yet optimistic.

In determining what "truthful aspects" of the situation to elaborate on many of the couples reported that their doctors were "open and honest," in stages. That is, instead of coming right out and telling the patient and spouse the entire diagnosis, many doctors opted to forewarn their patients before, during and after diagnostic testing about the possibility of cancer in order to prepare the patient and spouse for the "bad news." (Note the doctors' use of the pronoun we, which seems to be communicating the idea that the patient and physician are now a new system and can be identified as such.)

male patient: The doctor came in and told me that we had

complications (He had just gone in to have his

prostrate "reemed" out.), and, that we would

have a biopsy. When they did that, that's when

they found the cancer.

female spouse: He said he found a spot on the lungs and he

wanted a routine x-ray...Later, he said there

was a change in the size of the spot and they

put him (her husband) in the hospital for

routine tests..Then, he told me, after it

was all over that it was cancerous.

female spouse:
You asked us how he told us. That's how it started--"We think we have a problem." The first few tests that he made, he was 99% sure and he kept dropping little hints, like "This is most probably a cancer situation." But, until he had all the tests in, he never really said, "This is the type of cancer you have." But, he was giving little hints all the way along.

male patient:
Dr. B said, "I think we've got a problem, so you'd better check in."

Finally, all but three couples expressed the following type of opinions about the type of language their doctors used, not only during the discussion of the initial diagnosis, but also throughout the various phases of the disease.

female spouse:
They (the doctors) spoke a language we could understand.

male patient:
We felt free to ask if we had any doubts....You felt that they would answer any questions that you would have.

Although the reported patterns for communicating the diagnosis all

deal in the realm of an "open and honest, positive yet realistic" type
of communication, a closer analysis of the responses shows that none of
the reported diagnostic communication episodes dealt with the feeling
level of the patient and spouse. Talking on an informational or content
level about the illness is a type of communication level which seems to
be preferred not only by physicians, but also by medical personnel in general
and patients and spouses,in particular (see Pattern IIIb,p.211). This type
of communication process is further described in the following pattern:

Talking About the Illness: Medical Staff (Pattern I_2).
In order to preserve personal boundaries and role functions,
and in order to maintain emotional and interactional stability,
the medical staff and/or hospital personnel communicates with
the patient and spouse on a content (factual scientific) level
only. The meaning of the illness is defined and conveyed
through the physical care of the patient. The word and topic
of cancer is avoided during communication interactions with
the patient and spouse.

The literature supports this communication pattern, suggesting that
physicians and hospital personnel in general "often spend more time
trying to avoid personal and intimate issues than they would use in
simply listening to their patients" (Artiss and Levine, 1973, p.1210).
Physicians and nurses alike may avoid feeling level conversations with
the cancer patient and his/her spouse because "they may feel guilty and
inadequate because they cannot do more to help the patient get well,
or because they fear they will hurt if the patient dies" (Blumberg
et al., 1980, p.90). A content level discussion of the disease (i.e.
"How does your incision feel?" or "Do you need a pain pill?"), simple
"cheerfulness" or a noncommittal attitude by hospital personnel may

mask their fear and/or uneasiness about the patient's death or their own thoughts on death or dying. If the caregiver does not or has not been coping well with the anxiety and frustration caused by working with life-threatening crises, s/he may retreat to dealing with the cancer patient on a physical or scientific level only, even going to the extreme of avoiding the word <u>cancer</u> itself in order to avoid the emotional impact that the word/idea may precipitate.

This circumscribed communication may also develop because "Treating cancer today places severe demands on time, emotion, and skills" of the physician and hospital in general (Rosenbaum and Rosenbaum, 1978). For medical caregivers, dealing with the complex psychosocial issues of cancer may be too demanding or overwhelming, not only physically and emotionally, but also practically (i.e. too many patients, too little time).

Finally, the content level type of communication that so often occurs in medical settings may be the only interactional level of discussion which the patient and/or family will allow in their dealings with medical caregivers. In many cases the patient or family sets the example for all involved in the cancer crisis when they will only, for example, talk "doctor, treatment, or appointments" but will not share their fears and concerns with those around them.

The following sample responses illustrate the communication pattern that eight out of ten couples described in discussing their experience in being in a hospital setting:

female patient: No one at the hospital talked to me about
                    my cancer. They didn't even mention the
                    word.

wife: That's interesting. I do not remember a
                    single nurse or person caring for T in the
                    hospital room ever mentioning the word
                    cancer. I guess I just assumed that they
                    read it on the chart and just didn't say
                    anything because they never asked.

husband (patient)   No, or anything relating. If they came in to
                    clean an incision or this or that or the other
                    thing, why they did it. They were doing a job.
                    Not coldly, mechanically or militaristically,
                    or anything. They had a job to do and came
                    in and did it. There would be no reason to
                    discuss whether you had a...whatever.

male patient: No, the staff did not talk to me nor mention
                    the word cancer when I was in the hospital.
                    I presume they see it all and this is the
                    standard way of handling this. It was just
                    another sickness....

husband: The hospital treats me all right....Nobody
                    ever talked to me about the cancer, but then

	that's not their job.
wife:	Yeah, T's care has been good, but I don't remember anyone every mentioning how he was feeling.
husband:	They didn't. They would just say things like "I want to look at your dressing." Things like that....never anything like "How are you feeling?"

It should be noted, as can be observed in several of the sample responses, that although the couples mentioned that no one in the hospital setting talked to them about their feelings or addressed the topic of cancer itself, none of the respondents appeared to be upset about this, with many of them giving the interviewer a reason why this type of communication did not take place (i.e. not their job, don't have the background, etc.). However, responses from other interview questions lead this researcher to believe that a content-level type of communication is one of several contributing factors that precipitated the reactions and responses described in the next major category.

Initial Responses (Major Category II). The marital dyad's initial response to being assimilated into the medical system.

The responses grouped under this category all deal with major reactions, concerns and fears that the patient and spouse experience after learning of their life-threatening diagnosis and after finding themselves, as a consequence of that diagnosis, being forced to enter into the foreign,

fear-provoking, frustrating and sometimes dehumanizing world of illness and medicine.

> Loss of Control (Pattern II_1). As a response to being
> incorporated into the medical system, the couple feels
> a loss of control. They feel controlled by external
> forces, such as (a) the nature of the disease, its
> implications and its treatments, and (b) the medical
> profession and their need to maintain their roles of
> "decision-makers" and/or"controllers." The spouse and
> patient also feel a sense of helplessness over the loss
> of control they experience concerning their homeostatic
> patterns of lifestyle and role functions. As a part of
> the loss of control they experience because of the doctor
> "taking-over" the direction/functioning of their marital
> system, some patients treat their doctors as "demi-gods,"
> whether by choice or out of fear of disapproval.

Miller et al. (1976) note that illness in general and cancer in particular often elicit a sense of helplessness in patients that makes them feel as if they are controlled by external forces. Blumberg et al. (1980) observe that although some patients happily give up their control and enjoy the patient/dependent role, for others "surrendering to the sick role, even temporarily, is difficult" particularly for those "who value their independence" (p.24).

Because of the hierarchical functioning of the various systems (individual, marital, familial, social, etc.), it is only natural that some dependence on members of other systems will and does occur. But, the disruption of former role functioning and the consequential dependence on spouse, doctor and family because one has cancer can be particularly distressful or disgusting to the patient whose self-esteem is derived primarily from his or her pre-illness role.

Feelings of helplessness, anger or distrust may develop as the

patient and spouse find not only that their own roles are being
changed by outside forces, but also their homeostatic lifestyle
patterns and routines, even their plans for the future, as is
illustrated in the following sample responses:

male spouse:	We always went, did everything together, even if it was just window shopping. It just don't happen anymore. I'm sure my life is changing, my life-style. I feel like I have to go to work 'cuz we spent all our cancer insurance and now it's costing our savings.
husband:	Boy, it changed our life an awful lot, I'll tell you.
wife (patient):	It certainly slows everything down... everything.
husband:	She was awful active....Now she can't do anything of it.
female spouse:	He (her husband) used to be such a good eater. He really enjoyed the meals I cooked for him. Now when I fix something, he can't eat it. When you fix a nice big meal and he takes one bite and it comes right back up, I get disgusted. It doesn't pay to cook

'cuz I eat it and I don't need it.

female spouse: We can't do the social things that we did

before--bowl, get together with friends,

see a movie. It's difficult even to have

friends over. He can't be around smoke

and crowds or it will start him hiccuping.

wife: J and I used to travel everywhere together.

husband: We loved to go out, eat dinner and have

a few drinks, entertain friends. No more

of that, not now since R has been feeling

so lousy.

wife: Some days I find it hard to move off the

couch.

Along with the changes in lifestyle patterns and routines that
cancer precipitates, the disruption and change in roles that the disease
can cause may give rise to a sense of worthlessness and dependence in
both the patient and spouse:

male patient: I'm fortunate in that I've got good people down

at the store. They stepped in and took over and

filled in the holes, took over my work. Now I

go down there and feel like a fifth wheel because

they pretty well established a new way of handling

things....I don't feel threatened by it, but

I guess I could say that I'm sorry that I'm
not more indispensable.

male patient: It bothers me to see her (his wife) shoveling

the sidewalk, that I can't be of help, do it

myself. That you're not doing your fair share.

male patient: Since I've been sick, my wife has taken to

doing strange almost insulting things--like

reminding me to plug in the car or telling me

where to turn (the car) to get somewhere. I

keep my anger to myself, but it's as if she

thinks my illness has made me a baby or deaf,

dumb and blind.

male patient: The only thing I can say is that they (his

family) want to treat me as a baby....

female spouse: They (my friends) don't think you can do any-

thing because you've got responsibilities at

home, which is true. Like my sorority, I was

the head of so many different things going on

and then they took them all away from me....

You don't know really yourself how many

meetings you'll be able to make. Yet, it would

be better for me to get my mind on something else.

As can be seen by these sample responses, feelings of worthlessness and loss of control may arise not only from the change of role precipitated by the cancer itself, but also by the response of family members or friends who place the cancer patient or spouse in the "sick" role, which is equated with a child's role. Patients reported that they in general try to fight that "child's" role through such means as ignoring the role, trying to prove that they are capable of fulfilling former role label functions or by "speaking their minds," usually accompanied with outbursts of anger or frustration. It must also be noted that responses dealing with expressed feelings of helplessness and loss of control because of role functioning disruption, for the most part, came from the male patients, an observation which the literature in the field supports. Cantor (1978) notes that despite the influence of the women's movement, men are still expected to be strong, decisive, and able to provide financial support. Consequently, when illness and/or hospitalization occurs, and someone else in the family system has to assume the "breadwinner" role, the change for the family is particularly difficult and frustrating because of the system's inability to cope with the male's new situation.

Besides the role and lifestyle disruptions that cancer may cause, the very nature of the disease itself may give rise to feelings of lost control. Blumberg et al. (1980, p.24) observe that

> Uncertainty about the type and extent of treatment, as well
> as the duration of the disease, create an atmosphere of un-
> ending sickness. Further, there seems little the patient
> can do to stop the onslaught of cancer. Other diseases have
> concrete courses of action, that, if followed, hasten re-
> covery and prevent future illness. Heart disease, for example,
> can be controlled by medication, proper diet, regular exercise,

and cessation of smoking. Cancer offers no comparable course of action.

Feelings of loss control because of the nature of cancer and the sometimes questionable ability of the medical profession to cure it can be seen in the following responses:

male patient: This damn cancer. It just grabs hold of you and eats you up. Every day I become less and less a man. I have no control over it. I knew that I wouldn't; I knew that whatever the doctors did would be hopeless.

female patient: You kind of resent it (the cancer) in a way. I think the biggest feeling is you feel so help- less. If you've got a cold, you can take care of it, you can do something for it.

female spouse: Once the person admits that they have cancer, it isn't ever a situation of I had cancer, it is a situation of I have cancer, and it always will be. It's like an alcoholic. It may be in remission or it's not an active thing, but it's there. And, I think that's the hardest thing to deal with.

female patient: There's something so final about it. If they tell you you got some disease, at least you got hopes of getting over it. Even with open heart, look

at all the great things they've done with that. But, cancer is "that's it."

female patient: When you hear the word <u>cancer</u>, you think death. That's really what it means. These people who feel that cancer is curable are just fooling themselves, it's not.

male patient: Although I'm doing just fine, every little pain, every change in habit, like going to the bathroom at night three times instead of my usual two times, makes me think, makes me suspect that something is wrong, that they didn't cure it.

Besides feeling that cancer is a "death sentence" or an interminable disease that may disappear and then reappear for no particular reason, the patient and spouse may also feel helplessness over the implications and extensions of the disease. Cancer, in many cases, implies long, drawnout courses of treatments which may bother the patient both physically and mentally. As Brody (1977) notes:

Cancer patients face still another assault to their usual ways of coping with illness. With most kinds of illness, the disease makes you feel sick and the treatment makes you feel better. With cancer, in many cases, the patient feels quite well when his illness is diagnosed. It is the treatment that may make him feel sick (p.185).

Besides the emotional and physical impact such treatments as surgery, chemotherapy and radiation have on the marital system, the financial burden of these treatments also contributes to patients' and spouses' sense of lost

control. And coupled with the nature of the treatments, their cost, side effects and questionable curative power is the loss of control the marital dyad experiences by simply being under a physicians care. They must, of necessity, give some measure of decision-making power to the medical professionals in charge of their treatment plan mainly because these people have the knowledge and information to possibly make them well or at least better (the "power of life," as one patient stated). Many of the factors which contribute to the couple's sense that they have "lost control of the situation" can be seen in the following sample responses. Control by medical caregivers:

female patient: I feel like these people are doing things to me that I don't want them to. I've thought a couple of times what if I stood up and said, "I'm not going to do this (take radiation treatments) anymore." Well, they'll just say, "It's your body; you can do with it what you want."

female spouse: The doctors said it was up to T, it was his choice, or so they said, but they also said that he would live less than six months without it.

Loss of control due to nature and course of treatments:

female patient: I hate those treatments. It's ridiculous. They don't hurt, but it's getting into those

cold rooms, and those big machines....There is just something about the whole thing....I can understand why you get tired after awhile.

female patient: It's(taking chemo) like going to the hospital every other week to catch the worst case of flu you can imagine. And, after you've thrown up and thrown up and had diarrhea until you can't even get up off the toilet by yourself, then they reward you by telling you, "Well, all we can do is wait and see if the chemo is effective in keeping control of the cancer." Control! I wanted to shout at them, "Well, it (the chemo) damn well should be curing my cancer. It has destroyed everything else in my body!"

male patient: Sometimes I feel like everybody is making decisions for me. I get my hospital bill and I find that I'm paying for people that I don't even know. I'm taking drugs that make me sick; I'm getting radiation that makes me weak and it's all to cure a cancer that is going to kill me anyway.

The economic toll of cancer and the subsequent loss of dyadic or personal control:

male patient: I take pills for diarrhea and Metamucil for constipation, which the pills cause. I've got high blood pressure and diabetes, so I have to avoid eating much of the high nutritional stuff that the dietician recommends. I have pills to help me go to the bathroom and pills to help me hold back so I don't pee my pants (laughter). I sure feel like I've been keeping the local drugstore in business, I'll tell you.

male patient: I worry how I'm going to be leaving P with a whole lot of financial problems--doctor bills, hospital bills,....It scares me, but I don't know what to do about it. I know my insurance won't cover it all.

female spouse: It (the cancer) made us broke....When you're used to paying in cash or you don't get it....We're more in debt now than we ever could imagine.

female patient: You hate to save all your hard-earned money for your rainy day and then blow it on something like this.

Emotional toll on spouse and subsequent feelings of helplessness:

male spouse: I think seeing her suffer is the worst thing.

This has hurt me. I think, "Are we doing the right thing (taking chemo) or are we just pro-longing the agony?"

female spouse: I felt so helpless--seeing R in the hospital, continuously vomiting, continually getting worse, yet the doctors didn't have an answer. And, he was hooked up to all kinds of tubes.

male spouse: I don't know. There's times you feel like, boy, she's suffering the way she is--there's times you can't get out of the room fast enough, otherwise you can't stand it. You feel so helpless.

As the preceding responses illustrates, the emotional, physical and economic toll of cancer can be devastating to a marital or family system. And, through all of this devastation and disruption, the physician plays a very important and intricate part in the lives of the patient and spouse.

Mastrovito (1972, p.2874) notes that "Most patients view (and need to view) the physician, with his medical skills and experience, as their primary resource in confronting their disease. To them, he offers a shield against the confusion, helplessness and fear that accompany a diagnosis of cancer." A patient or spouse's reactions towards his/her doctor may, at times, seem like a double-edged sword. Many interviewees reported feeling helpless because of their doctor seemingly taking over

the control of their lives and lifestyles. However, many respondents
also observed that they looked to their doctor to always know the answers
and to cure them of their cancer (giving the doctor the responsibility
for their disease). Consequently, the doctor's "demi-God" image may be
a result of the patient and family willingly assigning the doctor that
role or it can be due to the doctor him/herself cultivating and pro-
jecting the image. The following responses reflect the contributing
factors to the "God-image" of the doctors:

male patient: All my life I've been in positions, jobs
where I made the decisions or directed the
show. When this happened to me, I thought,
"Well, I'm not going to be the take charge guy.
The doctor's gonna tell me what to do. And,
I have succumbed pretty much to what they have
directed....I think if it wasn't such a
grave thing, it might have been different.
I really felt relieved that I wasn't going to
have the responsibility for my disease. That
I was gonna do just exactly what they told me
to do.

male patient: I'm inclined to think that they're the experts;
what they say goes. I think that there might be
circumstances that I might be inclined to argue
with them, but by and large, the doctor is the

expert, I'm not.

female patient: You have to take care of yourself. You have
                   to stick up for yourself when you deal with
                   the medical people. They have this "God-image"
                   of themselves, you know, who are <u>we</u> to question
                   their judgment?

female spouse: No doctor likes to admit that they really don't
                   know what the problem is and they don't even
                   like to refer you because they're admitting,
                   "Hey, I've come across something..." No
                   doctor likes to admit that. But, I think to
                   the fairness of the patient they should sooner.

female spouse: (in talking about the difficulty she and her
                   husband are having concerning their situation
                   in approaching their doctor in order to ask him
                   if they could see a cardiologist since her
                   husband had had a heart attack while recovering
                   from cancer surgery) I know they (the doctors)
                   don't like to be questioned, do they?" (She
                   says that she told her husband to tell their
                   doctor that the "visiting" children were con-
                   cerned about his heart. Perhaps then the
                   doctor wouldn't be upset over their desire to
                   see another doctor.)

Patients sometimes fear that their doctor may abandon them or lose

interest in their case, as can be seen by several of the preceding re-

sponses, and, as a consequence, they may contribute to, create or simply

accept the "God-image" of the doctor. Fear of abandonment not only by

the doctor but by family and friends is a concern that many patient

and even spouses have in dealing with the cancer experience. Fear of

abandonment and isolation may develop because the cancer patient feels

s/he is personally unacceptable or may be viewed as unacceptable by

others. As Brody (1977) notes:

> Cancer is commonly perceived as an always fatal, and
> particularly loathsome disease, not clean and uncompli-
> cated like, for example, the frequently more fatal heart
> disease (p.84).

Sutherland et al. (1977) further elaborate on the subject by positing that

fears of unacceptability and isolation can be "greater sources of depression

than fears of recurrence....indeed, some patients would prefer to die of

cancer than face the issues" (pp.17-18). And, Severo (1977) notes that

"People who have cancer sometimes speak of themselves as the new lepers:

of being rejected, overprotected, and misunderstood, all the same time

and by the very people they go to for support" (p.42).

Responses from the patients and spouses in discussing the "dark

side" of cancer support these observations from the literature in the

area.   The following communication pattern was developed from and

because of these very same expressed concerns.

> Alienation/Isolation (Pattern II$_2$). Responses, fears
> and concerns the marital system feels in being assimi-
> lated into the medical system include the fear of
> alienation and/or isolation from others due to

unacceptability (cancer is "dirty" or "contagious"--the leper stage) or due to the social death syndrome (loss of quality of being "alive.").

Fears of isolation or alienation may stem from the patient's or spouse's personal reactions towards or opinions of cancer, or they may stem from other's reactions toward the patient and spouse. Blumberg, et al. (1980) note that "the unfounded belief among the general public and even the patient's family that cancer is contagious may result in ostracism" (p.21), an observation which is reflected in the following sample responses:

male patient:	It's a little difficult to get over the 1930's, 40's, 50's philosophy of cancer. Cancer was rated almost on the same level as venereal disease or something like that. We're old enough that throwing that attitude, I guess is the word for it, is a little difficult for us even when it happens to us.
male spouse:	Some of them, some of them, I think they figure cancer is contagious or something, you know. I noticed that.
female spouse:	T always used the same dishes and didn't let anyone else use his dishes or silverware. Even though he said cancer was not contagious, I think he was afraid I'd catch it.

male patient: I did notice today down at the office that I was a little hesitant to touch someone else for fear that they might in any way be offended. I wasn't worried about me; I worried about how they might feel.

Friends, family and even hospital personnel may physically and/or emotionally withdraw from or act differently toward the patient (or even the spouse) not only because of their unfounded feelings that the cancer is contagious, but also because they believe the patient will die (or is already "one of the dying" instead of "one of the living") because of the "death-sentence" type of attitude that surrounds an illness such as cancer:

male patient: He (the doctor) doesn't say much now, but I can tell that he knows I'm dying.

interviewer: How can you tell?

patient: Well, for one thing, I haven't seen a lot of him. I haven't seen a lot of any of the hospital people, which is just the way I want it.

male spouse: People say they'll come to visit and don't show. I don't think they ever meant it. Their loyalty leaves much to be desired, I think.

female spouse: People don't want to talk about it, or they

don't know how to talk about it. People don't come over....They'll call up, but it's real quick--"Do you need anything?" or "How's B today?" Well, now I just say fine because people don't want to hear it....People don't want to listen.

female spouse: I think more people come up to my husband and they act towards him as if they are thinking, "He doesn't look as bad as I thought he was gonna look!" People seemed to be surprised that he was doing so well. They think that cancer means, "This is it."

male patient: The only thing that I noticed a couple of times is that people look at you, your friends, for instance, and they kind of give you a good look-- "Well, I'll get a good look at him to see if next time I see him if he's going down hill." And, that kind of annoys me. It's my mental picture, "Why are you looking at me like that?"

male patient: My mother-in-law can't talk to me or share things with me since I've been sick. I think she has an attitude that my situation is much graver than it could be. (He then agreed with the interviewer's comment/question that the

mother-in-law is acting as if she already has
him dead and buried.)

Cancer can have a serious impact on the marital or familial system,
as can be seen by all the preceding responses in this major category.
But, the ten couples also reported, either implicitly or explicity, that
they were using adaptive communication techniques and responses in order
to deal with the new and very frightening crisis. The ways the couples
coping with and adapting to the cancer experience comprise the third
major category of results:

The Further Coping Responses of the Dyad *(Major Category III)*.

As a result of their forced joining of the medical system, the
marital dyad must adapt to their new roles and their new situations. In
learning to adapt to the medical system, the married couple tries to make
sense out of their new functions. They must learn the rules of the medi-
cal community while also learning how to adapt to those rules. The
patient and spouse ask themselves, "How do we view ourselves? How do we
renegotiate our communicating relationships and our new role labels? How
do we assimilate this new illness into our marital system?"

The diagnosis of cancer in a marital or familial system has reper-
cussions for everyone in the family. Each family will be affected by
the disease and in turn will affect the adjustment of others (Pearse,
1977). Marital partners experiencing the crisis of cancer and the physical
and emotional disruptions that accompany it do develop ways of coping with
their feelings, fears and concerns as well as with the changes they are
experiencing, as can be seen in the adaptive type of communication patterns

found in this major category.

In dealing with their sense of loss of control and subsequent feelings of helplessness, patients and spouses try to learn about their disease and conquer their "fear of the unknown," which is evident by the following reported communication pattern:

> Informational Processing (Pattern III_1). The marital partners become information processors. They try to gain intellectual mastery over the disease by seeking to gain information from credible outside sources. One spouse may fill the role label of "listener," "conveyer" and "filterer" of information for the other spouse in order to lessen the fear, intensity or threat the informational messages carry. The couple conveys information to members of their family and social systems in order to maintain stable interactions with them and in order to lessen the members' confusion and "fear of the unknown."

Educating oneself or one's spouse, family and friends about the disease can help those involved correct their misconceptions about cancer and prepare them to counter questions and misconceptions raised by others. Acquiring information, asking questions and seeking outside credible sources can also help the patient and spouse regain some sense of control, intellectual control, over the disease, as is illustrated in the following responses:

female spouse: There was a lot of light conversation (in the waiting room with the other patients), but anybody who really wanted to talk about or get ideas from other people, I got the idea that you could get the information easily....

female patient: The oncology people are simply wonderful
                   in their treatment of me. They give me
                   all the information that I need....

female spouse: B and I gave ourselves a fast education on
                   cancer when we first heard the diagnosis.
                   Having information helped us cope. It also
                   made us more positive about the disease.

male patient: (The diagnosis) immediately started us on an
                   intensive training program on our own to find
                   out more about different kinds of cancer,
                   whether they spread, what the prognosis is for
                   recovery....This triggered quite a learning
                   experience.

female patient: The "I Can Cope" series was an excellent source
                   of information. Hearing other people talk about
                   their experiences with cancer made us feel so
                   normal.

Other patients related that they used other outside sources for in-
formation gathering—such as friends or relatives who had medical back-
grounds, hospital personnel or volunteers, television programs and
literature that dealt with the topic of cancer and, perhaps most importantly,
other cancer patients and families who had or were experiencing the same
thing as themselves. The researcher observed that in several cases she

was used as a "credible outside source", not particularly from the stand-point of giving information dealing in the physical realm of cancer, but more in the psychological and emotional realm (i.e. "How do other cancer patients react, feel when....").

Once information is given to or obtained by the marital system, it may be processed by the dyadic partners in many different ways, but one of the prevalent ways described by the respondents was that of one of the spouses assigning him/herself, or being assigned, the role of "communication link" with the doctor. This role, which was usually filled by the female partner (whether she was the patient or not), involved listening, conveying and/or filtering news to the other spouse, particularly when that person was "not hearing" or accepting the information (see Pattern III_3, p.203, for discussion of "denial process").

The couples' observation that it was more often the woman who was doing the communicating with the doctor and the information processing for the dyad reflects the traditional sociological perspective (as discussed in chapter one) which describes women as the "expressive leaders" and"in-tegrators" of the familial system (Cohen, 1966). Several of the husbands in the study reported that their wives could better describe to the doctor how they were feeling, bothy physically and emotionally. And, as noted by both male and female spouses alike, when information was "unacceptable" to the male patient or male spouse, the female partner's communication of that information was perceived as less threatening, and more acceptable and understandable. As a consequence of the diminished threat, the male "receiver" was able to assimilate the message more easily, as is

illustrated in the following sample responses:

male patient: She (his wife) talked more to the doctors than I did, relating how I felt....She usually does more of the talking than I would.

wife: Strangely enough, I was picking upon them (the doctor's hints), but T wasn't hearing them at all.

husband: I wasn't hearing a thing. I really wasn't.

female patient: I don't know what I think about him (her husband) talking to the doctors. The thing is I don't know if they would make a very big impression on him. He's another one who will hear what he wants to hear and so I don't know if it would help an awful lot....He listens to what I'm saying.

wife: One thing that I was particularly pleased about was that when the doctor was ready to talk to him, he said to me, "I would like to have you go with me to the doctor, to the treatments, because I will hear only what I want."

husband (patient)   I know my own failing.

Finding, conveying and processing information both within and out-
side of the marital system is an important means by which the couple can
regain some measure of control over the impact of the disease and the
medical world in general. Conveying information to their communication
links in their familial or social systems also helps them to maintain
their pre-illness relationships with these members. Many of the patients
and spouses reported that when faced with friends' or family members'
apparent discomfort over what to say or how to open up the conversation
with them, they reacted to this "hesitation" by offering as much infor-
mation and positive insight as possible about their own or their spouse's
situation. The couples reported that this seemed to lessen the confusion
and to restore the previously achieved "safety" and ease in interactions.
The following responses illustrate this aspect of the couples' information
processing:

female spouse: The only thing I've noticed (as far as people
                  acting differently) is that they (her friends)
                  seem unsure of what to say. They talk about
                  this and that and the other thing, but I see
                  them hesitating sometimes, you know, not
                  really knowing how to open up the conver-
                  sation. So, I usually give them a blow-by-
                  blow description of what's been happening to
                  me, always being super "up" and super "positive."
                  That always helps to ease the tension.

male patient: Some (people) ask questions because they are
simply curious. But, you can always tell the
ones who really care. They ask you how you
are doing and you can tell they really mean it.
But, sometimes I get the feeling that what they're
really asking me is "Are you gonna live?" When-
ever I notice this, I just give them as much
information about my disease as possible, and
I slap a smile on my face and tell them that
everything is "thumbs up." That always seems
to make everything between us better.

male patient: I tell my friends and family just like the
doctor tells me. I don't want the doctor to
beat around the bush with me, and I don't
think that the people who really want to know,
who really care, want me to beat around the
bush with them.

Gaining information and intellectual mastery over the disease helps
the couple to maintain some measure of their pre-illness homeostatic
functioning. It also helps to reassure the couple that what they are ex-
periencing, the range of physical and emotional reactions, is normal and
acceptable.

Having information helps the marital partners to diminish their
"fear of the unknown." Creating some type of meaning or purpose out of

the illness helps to increase the couple's abilities to endure and cope

with the "why" of that "unknown." Bard (1977) notes that

> When first confronted by serious illness, most people
> establish some sort of belief in order to explain what
> has happened, even if this belief is not expressed
> directly (p.100).

For some patients, "establishing a belief" means finding a cause or reason

for their cancer, such as those patients who discussed their frustrations

over having "smoked for so long," or those couples who related their fears

about the hereditary cancer trends in their family tree. For others,

fnding or developing some type of meaning from the illness (not merely a

cause) becomes an important yet complex process by which they can cope

with the experience.

Frankl (1963) in his personal account of his experiences in the German

concentration camps during World War II, observes that those who lost their

will to live usually died, but those who were able to make some type of

meaning out of their very painful and humiliating circumstances were the

ones who were able to live through the holocaust. Adopting Nietzche's belief

that "He who has a why to live can bear with almost any how." Frankl further

elaborates that even when all the familiar goals in life are snatched away,

what alone remains is the last of human freedoms--the ability to choose one's

attitude in a given set of circumstances" (p. IX). This "last of human free-

doms," the ability to choose and/or create an attitude or a meaning from the

illness, is reflected in the following adaptive communication pattern:

> Finding a Meaning or Purpose (Pattern III2). The couple
> searches to find and/or assign a meaning or purpose to the
> illness in order to assimilate it into their marital system's
> functioning. The juxtapostion of life and death results in

new meanings or attitudes about life. Priorities change--
life is not taken for granted; people become important. The
patient and spouse develop a new inner strength and a more
positive outlook.

The meaning that couples derive from their illness is as individualistic
as the cancer experience itself. And, yet, there are several prevalent
themes that run through their responses.

For those patients and spouses who are at a particularly hopeful
stage of the disease (i.e. the chances for recovery look very good),
one of the common responses that the researcher observed was that of
being "fortunate" or "lucky":

female spouse: When people talk about cancer, this goes

                  through your mind, that so many times you

                  think of it as being a lost cause. But, in

                  our case, we haven't felt that way at least

                  not up to this point anyway. And when we

                  talk ourselves, he'll say, "I feel like I've

                  been really lucky." I suppose you can say

                  lucky or fortunate.

male patient: I think you are talking to people who have

                  had a lucky break. We've got luck to thank

                  for this....I'm sure you'd get more input

                  from somebody who might be terminal...

male patient: (Discussing people who are crippled or disabled)

                  I feel that I'm lucky that I'm not in that

category yet.

The illness, as reported by couples experiencing all different stages of its development, can precipitate a change in attitude about life and people. The meaning of the illness may be reflected through the couple's newly-found or newly-developed appreciation for the "here and now" and for the people who are important in their life:

female patient: You just enjoy every day you have. We
                     all live on borrowed time; life's a gift.
                     I can't worry about tomorrow or yesterday.
                     All we have is today.

husband (patient):   It does give you a different outlook on
                     life. Things that you might think are
                     important aren't as important, say, as just
                     your family, the closeness you could have
                     with them. I think that's one thing this
                     has brought to me.

wife: That life's too short; people put too much
                     importance on material things. We could be
                     millionaires and no amount of money is going
                     to make a difference in this situation....

Finally, meaning and purpose can be found in developing new inner strength and a more positive outlook about life in general and the disease in particular:

male patient: One thing that I have had to develop is patience with myself. I guess I have learned that I can live with this disability for a period of time. If someone had asked me in the past, I would have said, "No, I can't live with that. I can't be inactive for four or six months." Just like so many other things that I can't, why you find out that you can if you have to.

female spouse: I think I've learned to be more patient—to gain more patience. And, I've tried to be more positive, and I really didn't know I'd be that positive.

female spouse: (Discussing the threat of cancer.) Once you have it, you always have it. It's a constant concern....But, I don't intend to dwell on that because I tend to deal in the positive things and positive expectations.

male patient: There are days that you get depressed, but you gotta keep thinking positive and it will get better. It takes a little more time now. We take it one day at a time now. Work it that way....The doctors can't guarantee a cure. It

comes from part of your inner strength to fight it, you know. That has a lot to do with it....

Finding meaning in the illness, whether it is an attitude change, a better appreciation of life or people, or a newly-found inner strength, gives the patient and spouse a reason to continue and encourages them to find value and importance in the physical and emotional pain they must endure. Religion, too, can offer the couple a way to make sense out of the life-threatening crisis they are experiencing.

"In the face of catastrophic illness, many patients find solace and strength in religion" (Blumberg et al., 1980, p.24). For many couples, putting their fears about death into the perspective of a religious philosophy enabled them to not only cope with those fears but to find meaning from them, an observation that is reflected in the following communication pattern:

> Focusing on Faith (Pattern III2b). In finding a meaning of purpose for their illness, the spouse and/or patient focuses on faith to guide or to give them strength in coping with the cancer experience and its possible positive or negative outcome.

For many of the interviewees, the illness precipitated a new and stronger reliance on and appreciation of the meaning and purpose their faith has for them, as is illustrated in the following responses:

male patient: My illness has made me realize that we all will die and that we don't live forever, but that God is there to help us. He lends you

the support more than anybody could....

| female patient: | My faith has helped me the most. I don't even know what I would do without it. |

| male patient: | ...Her (his wife) religious faith means a great deal to her, so she is able to get things percolated down to where she can live with them, using her religious beliefs as a bent. |

Besides providing the patient and spouse with the means to cope with the disease, religion also can provide a reason for the illness. In answering the question of "Why me?" or "Why this"," many subjects reported that the answer to those questions was determined by a "higher" force--God. The meaning of the life-threatening illness was derived from their sense that "God's plan" would decide the course and outcome of the illness, and it was their responsibility to accept, but not necessarily fully understand, the "game plan":

| female patient: | I know I'm going to die. I've known it all along, and I accept it as God's will, although the pain, not being able to breathe. That scares me. But, all I do is think of what Jesus went through on the cross and that gives me strength. |

female spouse:	I believe that the Lord has everything planned for us and the way He gets there may not be the way we want it to be, but that's the way it's going to be.
male patient:	Well, when God wants me, He's gonna take me.... And, another thing, I can honestly say this, if it wasn't for all the prayers when I was sick, I wouldn't be here.
female patient:	Like I say, I'm thinking positive. But, if the good Lord wants me, He'll take me. I'm not going to holler "Whoa!" in the middle of the stream.

As Frankl (1963) notes,

> Man's search for meaning is a primary force in his life and
> not a "secondary rationalization" of instinctual drives. This
> meaning is unique and specific in that it must and can be
> fulfilled by him alone; only then does it achieve a signi-
> ficance that will satisfy his own will to meaning (p.154).

For patients and spouses alike, finding or developing some type of mean-
ing from their disrupted and sometimes chaotic lives can bring them a
sense of peace, purpose and/or control. As a result, the cancer experi-
ence can become something they can learn from and grow with, and some-
thing they can cope with, not simply endure.

Denial As A Coping Pattern

Another coping process that helps the marriage partners make sense

out of the confused and fearful state they may find themselves in upon
hearing a cancer diagnosis is the denying process. Weisman (1972) notes
that denial is not just a defense mechanism nor is it simply negating
the facts, but it is a "total process of responding within a specific
psychosocial context" (p.60). He relates that it is both an act and a
fact, "the act of denying and the fact of denial. Both depend upon
personal interaction to define what, how, and when denying takes place"
(p.61).

Weiseman notes that the "act of denying" is a process that has
four steps:

1. Acceptance of a primary and public field of perception
   (No one can deny by himself in utter solitude; he can-
   not deny unless a portion of that field is shared with
   someone else).

2. Repudiation of a portion of the shared meaning of that
   field (which may take place by simple negation, or a
   person may also behave inappropriately for the existing
   situation).

3. Replacement of the repudiated meaning with a more con-
   genial version (either directly or indirectly).

4. Reorientation of the individual within the scope of the
   total meaning in order to accommodate the revised reality
   (the threat is contained, and earlier relationships and
   prior conditions are restored).

5. The fifth step brings about the fact of denial (p.61).

The denial process, as Weisman discusses, can be evoked in response
to a potential danger or threat, such as that of a jeopardized relation-
ship with a significant key person.

   Hence, the purpose of denial is not simply to avoid a danger,
   but to prevent the loss of a significant relationship....This
   explains why patients tend to deny more to certain people than

to others. Patients who deny a great deal seem to do so
in order to preserve a high level of self-esteem. For this
reason, they need to preserve contact and stablize their
relationship with someone essential to self-esteem (p.63).

Weisman further notes that even when there seems to be no one in parti-

cular who could be threatened by a patient's illness or death, "the

patient himself may deny because he wants to maintain the status quo of

already existing relationships" (p.64).

The process of denial can occur in different context   and be communi-

cated in various forms. The use of denial by the patient and spouse,

either as a system or individually, enables them to maintain a simplified

yet constant relationship with others (Weisman, 1972, p.65). The fol-

lowing communication pattern illustrates how the couples use denial to

cope with their life-threatening crisis.

> The Denial Process (Pattern III_3). The couple collaborates in the
> denial process in some way, both verbally and nonverbally, in
> order to cope with the illness and the medical world as well
> as to maintain relational homeostasis and personal self-esteem.
> The process of denial can occur on three levels in the cancer
> experience: (1) denial concerning the initial diagnosis and/or
> facts of the illness; (2) denial concerning the implications
> or extensions of the disease; and, (3) denial concerning the
> outcome (that death may occur). Denial can be communicated
> in various ways, such as negating, minimizing, forgetting,
> "not hearing," mutually pretending, avoiding, being overly
> positive, suppressing, or by using mixed messages.

Because denying is a process, not a static event, the "degrees"

of denial are never constant. For example, a person may be a "major

denier at one moment and under certain circumstances may be a minor

denier in another situation" (Weisman, 1972, p.67). The three degrees

of denial that are noted in Pattern III_3 are all related to the possible

threat of death (whether the cancer situation is described as life-

threatening or terminal).

"First-order denial," denying or disavowing the primary facts of the illness, is the type of denial process easiest to notice as an outsider. It can take the form of simply not accepting the diagnosis (i.e. the patient who has been diagnosed as having lung cancer, but who refuses treatment, saying it is "just a cold that will clear up."), denying the clinical facts of an illness, such as denying what symptoms or pain could mean (and consequently delaying to see the doctor), or using "words as instruments of denial" (Weisman, 1972, p.68). In discussing the use of words as "instruments of denial," Weisman notes that the images and secondary meanings that the word cancer can evoke (decay, death, wasting away, corruption, and so forth) can be too threatening not only to the patient and family, but also to the doctor and/or hospital personnel (see Rule I_2), therefore all involved in the cancer experience may discuss the disease in euphemisms or in circumlocutions (p.68).

The following sample responses illustrate the various forms of first-order denial that the researcher observed her subjects using:

male patient:	We just live like we did before. We don't bring it (the subject of cancer) up unless it's like an appointment or something. But, we don't even talk cancer. We just talk doctor, hospital, going in for radiation, but we never mention the word cancer.
female spouse:	Now that I think of it, I had trouble saying

it (the word <u>cancer</u>) because I guess I was thinking that he really didn't have it since the doctor said it was discovered so early, so slow-growing--all the good things. I felt it was difficult to say it because maybe I felt that this really wasn't happening and that he was going to get over it.

female patient: (Concerning a breast lump she had) He (the doctor) thought it was benign. He said, "Now if there is any change at all be sure and come back." There was some change, but it didn't seem too significant to me at the time. By the time I made up my mind,....he really wanted to get moving on it.

female patient: You know, as far as what you think, I think you're more stunned than anything. And, then, when I first started going down to oncology, I thought, "What am I doing down here?" But, of course, then I felt pretty good....But, when the pain started coming, then you realize what you're doing down there.

interviewer: What is it like having cancer?

wife: It's not cancer.

interviewer:	Or having a tumor...a life-threatening tumor, right?
wife:	We don't even think of it as that.
husband (patient):	I guess we never really stopped to think about it. It's an illness right now....I have never personally thought of it as life-threatening.

As Weisman notes, "Obviously, first-order denial precludes second- and third-order denial. When facts are negated, it is unnecessary to consider their implications" (p.69). However, he also points out that first-order denial is usually short-lived, with most patients eventually accepting the primary facts of the illness and the diagnosis, but being unable to visualize the implications and possible extensions of the disease. When a patient uses second-order denial, he may retrospectively minimize his illness and rationalize strongly about his situation and/or future plans. A patient may also fractionate his illness and symptoms into minor complaints, so that the total illness will not seem so serious. And, as Weisman further observes, "Generally, patients who refuse to comment about their future and deny the possible implications of the illness are seldom very optimistic. They tend to postpone specific plans on one pretext or another ("As soon as this infection heals, I'll be on my way.") (p.71).

Second-order denial is reflected in the following responses:

male patient:	I am more inclined to ignore this illness.

It simply is not that big of a deal. Frankly,
I think more people get well more quicker if
it is ignored....this is the way I handle
this thing.

male patient: Sometimes you even forget, thinking you're back
to normal and you even forget how close you
were...you get back into the routine of what
you were before...you take things for granted.

male patient: She makes sure I take my medication, which I
appreciate, because I always forget about them.

male patient: (After the doctors talked to him and his wife.)
I told her not to worry that the situation was
simply not that serious, and that the treat-
ments would get us back to normal, which they
have.

female spouse: Once I got my husband out of the hospital, I
couldn't get him to go see the doctor. He went
right back to doing all the things that he was
before and he would just tell me "I'm feeling
fine. I don't need to see no doctor." God, I
almost lost my mind. He just wouldn't accept
the fact that his cancer was making some changes
for him. By the time I did get him to finally

go, he was in so much pain I thought he was

gonna pass out in the waiting room. Of course,

he just told the doctor that he had a chest

cold.

male patient: I keep telling "L" that the reason that I'm

not walking as much as the doctor told me to

is because of the lung damage I had earlier in

life and not the lung surgery. She just

doesn't understand that that's the reason I'm

not up to par.

Even though patients and families may eventually accept their cancer

diagnosis, with all of its complications and hazards, they may still

resist the conclusion that if the disease proves to be incurable, they

may die from it (the "inability to imagine personal death"). Third-order

denial, or denial of extinction, is found "only among patients who have

already acknowledged the facts of the illness and their extensions, and

face imminent confrontation with death. Aside from any philosophical

and religious belief, they will behave and talk as if their present

state would be indefinitely prolonged" (Weisman, p.73).

Of the three patients who openly acknowledged that they were dying,

only one patient talked as if she would be "going home soon to work on

the garden," even though her condition had so deteriorated that she could

hardly sit up. With all three terminally-ill patients, none had been

informed directly by the doctor that their cancer was incurable, but

all seemed to know that they were dying. Even the woman, who at several

points during the interview discussed "going home" and "getting up, get-

ting around and getting better," was able to describe to the interviewer

what she thought it would be like for her husband after she died. This

supports Weisman's observation that denial is not constant and can (and

does) occur in different degrees and in different forms. It also sup-

ports Hackett's (1976) contention that "Despite what has been told and

what withheld, most dying patients know about their illness" (see p.60

for discussion).

The following communication pattern illustrates another form that

the process of denial can take:

> Mixed Messages (Pattern III3a). Although they are collaborating
> in the denial process in some way, the dyadic partners are able
> to or allow each other to express "mixed-messages," responses
> which communicate their uncertainty about the future and the
> outcome of the illness. These mixed messages, which can be
> verbal and/or nonverbal, reflect a more rational view of the
> illness--balancing the positive ("look for, hope for the best")
> with the negative ("anticipate the worst").

Weisman refers to the state of "uncertain certainty" that this pat-

tern reflects as "middle knowledge," noting that it occurs somewhere

"between open acknowledgement of death and its utter repudiation" (p.

65). Mixed-Message types of responses communicate to the observer that

the patient or spouse is fluctuating between denial and acceptance, a

type of equivocation that may occur throughout the course of the disease.

This state of uncertainty and the patients' and spouses' consequential

struggle over knowing, yet not knowing, over being positive and sure yet

questioning and doubtful are reflected in the following responses:

male patient: Just like I'm telling you--think positive
about the thing. I'm sure that we got it.
I'm sure and then I'm not sure, until I find
out that I'm sure that I'm not sure.

male patient: I feel that they got it all because we caught
it in time, but then maybe they didn't.

female spouse: My husband and I don't openly discuss our fears
and concerns because there really isn't much to
discuss as we both feel that the doctors got it
all. But, we did clean house, if you know what
I mean....Get our finances in order, let the
kids know where stuff was, update our wills.
I guess it never hurts to be prepared, if you
know what I mean.

female patient: I don't want to seem that I'm too optimistic
about this because I do have moments when I
get a little panicky and I think that I don't
know where all of this (the treatments) is
leading, what's going to happen. I mean how
do I view myself? I like to think I'm heading
for a recovery, but then I think sometimes
that I just may be prolonging the agony. I really
don't know and I kind of get depressed over
that.

Mixed-message communication responses allow the marriage partners to express their fears and concerns in an "acceptable" way, either while alone or with each other. Using mixed messages also enables the dyadic partners to momentarily "get out of" the denial process (if they are so involved) without upsetting the marital system's homeostatic balance.

Another type of denial communication form, mutual pretense, also helps the couple to maintain their pre-illness homeostatic relationship. This type of pretense is described in the following pattern:

> "Let's Pretend" (Pattern III3b). The dyadic partners meta-
> communicate about how they handle their feelings. The
> couple reestablishes, builds and maintains their intimacy,
> in response to the threat of loss or change, by creating a
> reality that they both agree not to destroy. When asked
> by an outside observer, the couple can relate that they
> have assimilated the illness into their system by creating
> a new game of "Let's Pretend." The rules of this game, as
> the marital partners relate and agree to, include talking
> about the illness on a content (factual) level and being
> strong, positive and unemotional for and in front of the
> other partner.

This pattern is similar in nature to the type of communicative pretense that is described by Glaser and Strauss (see chapter one, p.51) in that it is a situation that may develop in response to the patient, family or even hospital staff members not wishing to openly confront the fact that an illness may be life-threatening or terminal. Because of the fear of the possible loss of control over emotions (i.e. "He'll just fall apart if we tell him the truth.") and/or the fear that communicating relation-ships will be changed (i.e. "People will be uncomfortable, embarrassed around me if I tell them how I'm really feeling."), the patient or some other person involved in the life-threatening crisis will begin the mutual pretense drama. Others then implicitly or explicitly consent to

"play their parts" in order to insure their "safe" participation.

The rules of the "Let's Pretend Everything Is All Right" game that the dyadic partners play together, however, are somewhat different than the rules governing the above-mentioned pretense context. Firstly, the "Let's Pretend" game in which the couple collaborates can be discussed and described to an outside observer ("This is how we are handling it.") Secondly, the pretense the partners create does allow them to talk about the illness on a content or factual level ("How was your treatment?", "What did the doctor say?", "When's my next appointment?"). And, thirdly, the "Let's Pretend" game functions not only to help the marital partners avoid confronting the possible implications or extensions of the illness, but it also helps them to restore and maintain their pre-illness homeo-static level of intimacy which has been threatened due to the illness and the entry of so many new people into their marital system.

As was noted in chapter one, the use of pretense by some married couples can be a less alienating and more adjustive orientation towards coping with a life-threatening illness than are role expectations that require "realistic" orientations about the possible outcome of the ill-ness or which assign the patient with some type of "privileged" status (Sheehy, 1977). The desire to maintain the "status quo" for many couples far surpasses their need for cathartic release of their emotions, fears and concerns through feeling level communication, as is illustrated in the following sample responses:

wife: After E. told me he had prostate cancer, I
                               hung up the phone and broke down. But, I

didn't go to the hospital that night. I
didn't go until I had myself together.

male spouse:
Oh, V., she just keeps it all inside. She's
really a strong person. There's only been a
few times when I've seen her get some tears in
her eyes, and when I do, I just turn my head
the other way. Crying is good for you, but
we don't cry in front of each other.

female patient:
It's not that we sit down and talk about it
(the cancer). The other night after the inter-
view, he (her husband) tried to change because
he sat down and he started to ask me about the
doctors, about my feelings. And, I thought,
"He's trying to sit down here and talk to me
about this." I would just as soon go along as
we have been doing because when something comes
up, I can tell him about it....I don't know if
you cover everything doing that, but it seems
to be a better way for me to do it.

male patient:
She (his wife) held up in front of me. As far
as me being sad or anything, I tried to do the
same thing--as if there's nothing to it....I
wanted to make her think it isn't all that bad.

female spouse: The most difficult thing for me through all of this is the thought of my husband's cancer spreading or coming back. We don't talk about it, but it's always in the back of your minds. We each know that the other knows, but we don't talk about that aspect of the situation when we're discussing it.

male patient: We act and talk like I don't even have cancer. Oh, it gets a little nerve wracking around appointment time, and both of us have a sleepless night, but we still act and talk like everything's "A-OKAY."

The "Let's Pretend" game can be played not only by talking on a content level or "being strong" in front of the other person, but it may also be played by avoiding the topic of the illness all together. Suppression of any discussion of the illness or fears and concerns about the outcome enables the couple to maintain their shared pretense of everything being all right (i.e., "If I don't say it out loud then it won't be real.").

Suppression may also function to maintain the couple's homeostatic patterns, both within and outside the marital system. Wortman and Dunkel-Schetter (1979) note that recent research suggests patients who can freely express their difficulties are especially likely to get negative reactions from others. They observe that the patients who are able to ask for help and to verbalize their problems are those who are least likely to get

sympathy. Considering the fears that many patients have about being unacceptable to or isolated from their family or friends because of the illness, one can see suppression functioning not only to encourage an "everything is all right" reality (to maintain homeostasis) but also to protect the person or persons involved in the life-threatening crisis from having to cope with the uncertainty, fear or rejection they might encounter if they start "talking about the illness."

Suppression may be a previous way of life for some or it may be a new way of coping with overwhelming uncertainty, emotional despair and fear of the future. For some, not talking about their personal crisis is the only way they are able to communicate about it, as can be seen in the following communication pattern and responses which illustrate its meaning:

> Suppression and Avoidance (Pattern III3c). The marital partners, either collaboratively or individually, suppress or completely avoid talking about the illness and its ramifications.

male patient: We (my wife and I) don't talk about my dying. It's easier if we don't. I want to protect her from the hurt.

female spouse: This has probably been one of the worst things I've ever gone through, and I've had to go through it alone. I haven't been able to talk to my husband about all of this--although I don't know what I'd say if I could. He just won't open up.

wife: We never said much (after the doctor told her husband he had cancer). I think he's kept his feelings pretty much to himself.

husband: I never had....It didn't excite me one way or another. I was never scared or anything like that.

wife: (How do you talk about the illness...) Not much. He doesn't....

husband: Why not?

wife: You don't talk much to me about it. You don't talk much to anybody about it.

husband: You was born once; you is gonna die once. You shouldn't have pity for yourself. What for? Nothing's gonna help. When that big boy says "Come on, let's go," he'll grab you by the hand and take you. You don't ask him why or when or where, so that's the way I feel....

wife: B. doesn't talk about it (his illness).

husband: Myself, I don't mention it. They know I have a problem, that's that, you know. When people stop and ask....

wife: He just says fine; he always tells them fine. He never lets on to the truth.

>Even when he's sick....I want to tell them
>that he's been vomiting today, but anymore
>I just say "fine. We're hanging in there."
>People don't want to hear, unless you're
>with somebody who has had the same type
>of problem.

husband:	(How did you/do you talk about the illness) We never really did.
wife:	We just did what we think is right, and, think it's gonna get better every day.
husband:	We just kept it to ourselves.

As can be seen from the preceding sample responses, the couple does not always collaborate in their suppression or avoidance of communication about the illness. In many cases the researcher observed that one of the dyadic partners, usually the male, was not talking, while she also noted that the female partner (whether she was the patient or spouse) was expressing more concern and emotion in discussing the life-threatening situation. This may again relate to the traditional sociological view of women being "expressive" and men being more "task-oriented." And, it may again support the researcher's observation, as noted in the beginning of this chapter, that it seems to be more difficult for the male to change from the "protector," "breadwinner" or "patriarch" role to the role of either a patient or caregiver to an ill spouse. Remaining "strong and "silent" can be one way the male respondents cope with the uncertainty and confusion caused by the illness.

When only one of the partners was suppressing, the researcher did observe that the other spouse (1) was able to discuss the situation in front of the partner or with an outside observer, (2) was able to non-verbally communicate her frustration over the communication breakdown (usually through tears, anger), and (3) was able to use communicative links outside of the marital system in order to "talk out" her feelings. Using these three communication outlets thus appeared to help the female partner to cope with and maintain the homeostatic pattern of suppression and avoidance used by her husband, as is illustrated in the following communication pattern.

> When Suppression Is Not Collaborative (Pattern III3d). If suppression is not a collaborative effort, that is if only one of the marital system's members is avoiding or suppressing, the other spouse may use outside sources and communication links in order to express feelings and discuss the illness and its possible ramifications. These outside communication sources help the spouse to cope with and maintain the homeostatic pattern of suppression that the other spouse has dictated. Nonverbal communication about the spouse's frustration is allowed within the marital system's boundaries.

As discussed, many different factors may contribute to a person suppressing or avoiding the topic of his illness (i.e. denial, fear of loss, change, stereotypical upbringing), but whatever the contributing factors are to the process of suppression, the fact that someone is not talking or sharing about the illness or his concerns can cause many problems and frustrations for those involved in the life-threatening crisis. Outside communication relationships can help to alleviate some of the tension and lack of conflict resolution within the system, but the spouse who "wants to talk" still may be faced with much distress, as is illustrated in the

following responses:

female (patient):	B. won't talk to me about my feelings or what I'm going through, so I depend on my two best women friends and my # 1 daughter for support. At least with them I can let it "all hang out," if you know what I mean. But, the situation still upsets me. He's the one person I want to talk to.
husband (patient):	My kids were upset, but we don't discuss it when they come to town. It's not something I want them to talk about with me. As I said before, you can overdo something like that.
wife:	My kids I can talk to a lot, thank God. Although they don't come over a lot, at least I can let loose with them.
husband (patient):	When I have problems, I keep them to myself....
wife:	Oh I can air it out at him, but he only sits there....
husband:	I think we understand each other, but it frustrates her that I don't let anything out. I find it hard sometimes. I usually

	keep it to myself most of the time. I find it harder sometimes to let people know my feelings....
wife:	I usually find someone to talk to.
husband:	Most of my friends don't know. I don't discuss my private business with them.
wife (patient):	Well, I can certainly say that at times like this you really find out who your friends are....The ones who have stayed by my side have really been a help to me....
male spouse:	I don't talk about it (his wife's cancer). I dread to think....I don't know whether it's next month or two weeks from now or six months from now....I don't think she's got much more time since she's filling up with water. As far as preparing myself, I try to overlook, like everything's all right.

Other Adaptive Coping Patterns

Seeking outside help during a marital or family crisis is a very common and acceptable way of coping with the situation, especially for those whose boundaries are permeable enough to let them "reach out" to others. In a life-threatening crisis such as that created by a cancer diagnosis, the response and support from family and friends can be seen as a strong contributing factor in helping the marital system restore

the balance and control that it may have lost upon entering the medical world. No matter how the couples initially described their coping or adaptive processes (denying, suppressing, "Let's Pretend", finding information and so forth) at least one and usually both dyadic partners in each of the ten couple interview sessions reported how important the support of friends and family was to them personally, to their spouse, or to the couple as a unit. And, as the following communication pattern illustrates, the support is not necessarily "sought" but may be given freely from others:

> Family and Social System Support (Pattern III4). In reaction to its being assimilated into the medical world, the marital dyad's family and social systems respond with support in the form of concern, caring, interest and affirmation in order to maintain and reaffirm the relational and emotional stability of the marital system itself and in order to reaffirm the couple's ongoing relational link with its kindred systems.

As was discussed in chapter one, a patient's illness has an impact not only for the patient,but also for larger marital, familial and social systems. The dyadic partners' fears of being viewed as "unacceptable," "different," or "not normal" because of the cancer diagnosis can be diminished by the positive response of friends and family, whose concern and caring can assure both of them that they are "okay," and that they are not alone in their anguish. Family members or friends not only provide emotional and physical support; they also give the husband and wife opportunities to privately ventilate feelings, emotions and fears without disturbing the homeostatic balance between the partners. The importance of the support of family and friends to the marital system's functioning and coping abilities during their cancer crisis is reflected in the

following sample responses:

wife (patient):	Friends' support, doing little things for me have been so nice.
husband:	Everybody just wishing for the best (has been most helpful).
wife:	Dr. D. told me the first time I saw him, he said, "You know, you've got to rely on other people." It was a statement that I really didn't understand until these people all started doing little things, and I thought, "This is what he meant. He said, "Talk to other people about these things. You've got to rely on your friends now."
female spouse:	I have had a lot of support from my prayer group, from my church people. In fact, our assistant minister came up and talked with me every day for four days up in ICU. So, I have had a lot of support which has helped me cope with it (her husband's illness).
male spouse:	I'll tell you, family unity is the best thing, the best medicine in the world.
female spouse:	I had at least three cards and notes sent to

me, not addressed to my husband, but to me,
asking how I was doing and if there was any-
thing they could help with, if they could
make telephone calls for me....It just
meant everything to me, and some of them I
did use.

husband (patient):	Friends are very supportive....
wife:	And concerned....
husband:	Offering all types of support.
interviewer:	What kinds of responses did you find helpful?
husband:	Not wanting to talk about the disease itself. Waiting for you to tell them about it. Not much input from them inquiring about what was done, the procedures. More, "How do you feel?" Waiting for me to tell them if I want to tell them.
female spouse:	Religious faith isn't a particular big deal for us; I wish it were. I guess if I felt like I could talk to God, since I can't talk to my husband, it would help. I guess what has helped me the most is my friends and my kids. Their support and concern has been wonderful. I'd be lost without it, lost....

female patient: One of the things that I would have to say is

the way that people have rallied around.

Really, they amaze me. After all, it's been a

month since I've had this and they are still

doing things. And, I think, this is really

wonderful.

Through their friends and family, the couple can be reassured that

they are loved, respected, cared for or simply thought of as the illness

progresses or regresses. In the midst of confusion and uncertainty, the

dyadic partners can find confirmation and affirmation from those who care.

And, through the chaos, they can find some level of detachment and release

of tension through their own use of humor, as is illustrated in the next

adaptive pattern.

> Sense of Humor (Pattern III$_5$). In trying to cope with the
> uncertainty of the illness and the stress of being in a
> "foreign" system, the medical world, the dyadic partners
> use humor to achieve some level of detachment from their
> ongoing cancer experience. "Laughing in the face of danger" (or
> death) helps them also to reduce the stress and tension
> of being in an "uncertain," high-stress situation and
> environment.

In his discussion of the coping processes used by his fellow inmates

and himself while they were in the German concentration camps, Frankl

(1963) notes that

> Humor was another of the soul's weapons in the fight for
> self-preservation. It is well-known that humor, more than
> anything else in the human makeup, can afford an aloofness
> and an ability to rise above any situation, even if only
> for a few seconds" (p.68).

He then recounts how he and his friends were able to develop a sense of

humor, an ability to look at their daily lives, which were filled at
times with horror and suffering, in a humorous light: "We laughed and
cracked jokes in spite of, and during, all we had to go through...."
(p.71).

The couples' use of humor as an adaptive mechanism proved to be an
"emergent" proposition which the researcher discovered while "in the
field" (McCall and Simmons, 1969). None of the pre-planned interview
questions dealt with the use of humor nor had any literary sources
indicated that a sense of humor was an important coping mechanism.
However, as is illustrated in the following responses, the subjects
related that having and using a sense of humor was very important and
very helpful in dealing not only with the day to day problems created
by the illness but it also helped them to deal with their personal fears
and concerns about the outcome.

husband (patient):	I kid with him (the doctor); I tell him stories or jokes. And, you know, he'd laugh and say, "You know, we should have a little more of this laughter because this stuff is so serious, and you see these people like this day after day. It's a pretty rough profession."
wife:	We need it (a sense of humor).
husband:	We enjoy it.
female spouse:	I do think a good hearty laugh does help to make the situation better, and it does

relax a person and ease the tension and about

the...diagnosis. I hate to say his "illness"

because he really doesn't seem to be ill.

male spouse: I was brought up believing that a sense of

humor is essential to living.

female spouse: While my husband was in the hospital, I said

something and we both broke out laughing. Dr.

S., who was in the room at the time, turned and

quietly said to me, "Do you know what's going

on here?" I said, "Oh, yes I do." Apparently

he thought it was kind of strange that I would

laugh, but it was my way of dealing with the

cancer.

male patient: You've got to have a sense of humor otherwise

you'd go crazy. Some of it gets to be so absurd,

you simply have to laugh!

Blumberg et al. (1980, p.20) note that "From the time of diagnosis,

the word cancer has elicited various responses from the patient as he

attempts to cope with a possible threat to his life--especially life as

he knew it before the diagnosis." The preceding categories describe some

of the various ways husbands and wives deal with the threat to life, life-

style and to loved ones. However, the full coping picture the couples

paint would not be complete without discussing the final process that the

dyadic partners use to deal with their crisis:

> Illness Precipitates New Communication (Pattern III$_6$). The
> illness and consequential active participation in the medical
> world precipitates new topics for discussion and new communi-
> cation about or sharing of feelings for the dyadic partners.
> New communication channels open up as, for some, it becomes
> "easier to talk about the cancer."

Although many of the categorical results deal with denying, sup-

pressing, or discussing the illness on a content level, the couples also

reported that for many of them (even ones who are "mutually pretending"),

the illness has helped them to talk more openly about their experiences

and reactions not only with friends and family, but with each other.

Because, as Weisman noted, very few coping patterns are used constantly

or consistently throughout the course of a disease, talking and sharing

openly can occur just as denying or suppressing can. Factors which may

influence what type of coping mechanisms are used can involve (1) the

stage of the disease, (2) the amount of fear concerning the loss of self-

esteem or the jeopardized relationship, (3) pre-illness coping and communi-

cation patterns (i.e. the "state" of the marital system), (4) stereo-

typical differences (is the patient male or female?), and (5) who is

involved in the communication interaction ("I can talk to you, but I don't

want to talk to my wife. It will just hurt her"). Taking into account

these factors along with the idiosyncratic ways that many people deal

with crises situations, one can understand how an illness such as cancer

can cause people to deny at certain times, while they talk or share at

other times.

The following responses illustrate how the cancer crisis has opened

up new communication channels, both verbal and nonverbal, for the

respondents:

female spouse:	I really think that since we went to the "I Can Cope" series, though, that we talk more freely about it (her husband's cancer). Not that I think there was a difficulty in talking about it before, but I think maybe it comes up a little more often. Maybe it comes up more easily.
male patient:	It's getting easier to talk about it as I get better....I didn't want to talk about it when I felt so awful. I was so sick to my stomach, I didn't want to talk about anything.
wife (patient):	You know, I think it's easier to talk about some of those things now than it was before. (Note: This patient was near death at the time of the interview.)
husband:	We've been pretty open about everything. We even went over and changed our wills.
wife:	I think it's been easier to talk about some of that stuff....(before) it wasn't real.
female spouse:	In some respects, I think maybe the communication in the family has been better from what it was....They're (the children) a little bit

> more willing to talk about the fact that their
> dad is sick than they would have before.

male patient: ....We have the last few weeks talked about a
few things that we never have. Myself, I find
it hard sometimes to do it. It takes a long
time before I bring up something that's on my
mind. (note: R. has been feeling better the
past few weeks due to his radiation treatments).

female spouse: We are more aware of cancer, of course. And so
we are more aware of things on TV about cancer
and then we discuss it.

Final Comment On the Results

The psychosocial adjustment to a disease such as cancer may precipitate various and uniquely individual responses from those involved in the life-threatening crises. Recognizing a pattern of response or behavior in people experiencing a life or death situation is only the first of several steps that will enable researchers or outside observers to understand how these patterns and coping mechanisms function for those involved. Although many of the patterns discussed overlap with each other, each fulfills a unique service in enabling the patient, spouse, family or friend to cope with or come to terms with the cancer experience in his or her way and in his or her own time frame.

Communication Characteristics

Following is a discussion of general communication characteristics

which this researcher observed or inferred from her subjects' behavior and responses. For the purpose of this study a "communication characteristic" is described as (1) a similar response or behavior which was given by or observed in 3-5 of the couples, or (2) a type of communication pattern, response or behavior which the researcher felt was insightful in its contribution to a better understanding of the cancer experience. These communication characteristics, along with the categorical results, help to reflect a more complete picture of the lives of the married couples as they go through their life-threatening crisis.

Weisman (1972) posits that there are three phases of personal response to the course of a potentially fatal disease:

> The Primary Recognition State, Stage I, covers the period
> from a patient's first awareness that something is amiss
> to the time of the definitive diagnosis. Stage II, Estab-
> lished Disease, is an intermediate phase which embraces
> events between a patient's initial response to the diagnosis
> and his reactions prior to the onset of the terminal period.
> Stage II also pertains to the periodicity of the illness,
> its relapses, remissions, progress, and periods of arrest.
> Stage III, Final Decline, begins when a patient undergoes
> unmistakable decline towards death. It ends when death is
> at hand (pp.98-99).

Because the respondents in the study were experiencing either the "established" or the "final decline" stages of the disease, the type of communication and language used in the recognition stage cannot be analyzed from a "content" perspective but only from the respondents' retrospective analysis about or observations of what they said or felt.

The subjects reported that for many of them, the period of recognition that preceded the actual diagnosis was characterized by their inner suspicion that something was wrong, yet their consequential delay

or postponement in going to see a doctor. For example, a woman who had a suspicious breast lump watched it change but did not think the change was "significant enough" to go back to the doctor; a man had been having urinary problems for two years before finally seeing his physician; a woman had been spotting for months at different times, but rationalized that perhaps she "really hadn't gone through the complete change of life five years before." Finally, there was a woman, a heavy smoker, who had experienced a terrible hacking cough and loss of weight for over a year, but who, according to her husband, had to be literally dragged to the doctor in order to have a checkup. In each of these crisis, the patient reported that she or he did not mention or discuss the physical symptoms or the personal fears that were being experienced. It was as if they were combining an "out of sight, out of mind attitude with a growing sense of vulnerability" (Weisman, 1972, p.103).

Even before hearing the actual confirming diagnosis of cancer, several patients, male and female, alike, reported that they "knew that it was cancer." Their responses show, however, that their observation about the diagnosis was not due to any particular insight or medical information about the disease, but more of a fatalistic fear that seemed to be centered around the thought that (as one patient reported), "Of course, it has to be cancer. What else could it be?" This response supports the conclusion that Brody (1977) and many other researchers report that cancer is, indeed, one of the most feared diseases of mankind. Because one out of three people is contacting it (as the Cancer Society now reports) and because of the nature of the disease and its prevalence in the news and in

popular literature, one can see why many people's first thought in viewing their physical symptoms is "I wonder if it's cancer?" Of course, the "wonder" or suspicion sometimes becomes replaced with "self-medication, optimistic rationalizations, selective disregard, (or) avoidance of whatever might be a reminder of a serious illness" (Weisman, 1972, p.103). And, until an actual diagnosis is made, every potential patient is alone with his/her suspicion and uncertainty.

All of the ten couples in the study had progressed through the recognition stage and were either dealing with the treatment, remission, arrest, or terminal stage (three of the ten patients were near death when they were interviewed). The responses from the couples who were experiencing the "established" stage of their cancer yielded many unique communications patterns, as already discussed in this chapter. Generally speaking, this researcher observed the balance between denial and acceptance changing for these couples depending on their physical and emotional states, and depending on the type of question being asked, and whether they were answering it in the presence of each other. Their responses also reflected their need for control and their need to plan for the future (i.e. go back to work, travel). Their communicative responses were, for the most part, hopeful and positive, although they were sometimes balanced with uncertainty about the future. In the interviews with these couples the subject of death or dying did not come up, unless it was in a religious context ("When the good Lord wants me, He'll take me."). The researcher, too, did not feel it appropriate to ask the couples how they felt about the possible death of the patient or "life without him or her."

Those patients and spouses experiencing the "final decline" of their disease could talk about their deaths and could describe what they felt life would be like for their spouses after they were gone. An analysis of their responses shows that none of the patients made any references to any long-term goals or plans for the future, although one husband and wife discussed their mutual wish to have the wife "come home." The issue of control seemed to be less important than the question of quality of life ("Will these treatments just prolong the agony?"), particularly because the deteriorated physical state of each of the patients had already diminished much of their autonomy. All three patients and their spouses admitted that death was imminent, but they did not admit this in the presence of each other. And, although all three patients expressed their desire to die at home or be at home, all three died in the hospital, a fact which may be partially explained by these patients' expressed fear of being a burden to their families.

The other communication pattern that seemed to differentiate these patients from those who were in the "established"stage of their disease was what this researcher, in her observational descriptions, termed a "flat" quality about the communication interactions. The responses reflected little emotional inflection, eye contact was sometimes poor, and, although the responses seemed honest, sensitive and well-thought out, they seemed to miss the vibrancy of tone and meaning that some of the other couples' responses had. To understand this the researcher took into account the physical state and consequential drug treatments that the patients were receiving, and she also considered the "letting go"

process that Kubler-Ross (1969) observed in many of her patients as they neared death. It was as if the patients were, in reality, saying: "I understand this is important to you, but it's not to me anymore. All of this is behind me now," which would be an understandable reaction in their present state.

By saying that the stage of the disease can be a good indicator of the type of communication being used, this researcher does in no way want it to be concluded that certain patients are going to talk certain ways because of their physical status. What is important about this observed communication pattern is that being aware of the context or disease stage may help the caregiver or family member to better understand what a patient's response or behavior means or how it functions for the person involved in the life-threatening process.

One cannot overlook the importance and function of sexual communication for the patient and spouse. Although the sexual implications of cancer and its treatment are "varied, complex, and difficult to generalize for the entire cancer population" (Blumberg et al., 1980, p.43), this study's results did support the contention that Lieber et al. (1976) made (see chapter one, p. 70) in which they reported that couples experiencing potentially terminal cancer situations (the patients had very poor prognoses) experienced a decrease in sexual intercourse or the desire for it, but an increase in desire for nonsexual physical closeness. Five of the ten couples reported that they were doing more "physical comforting"—holding hands, embracing, kissing, patting or caressing. Of these five, four of the five females (whether patient or spouse) reported that

there had been no sexual contact ("What sex?") since the onslaught of the disease, but their husbands all reported that there were no changes in the physical relationships with their wives, a difference in response which was also noted in Lieber's study. To understand this disparity Lieber and her associates contended that the women in their study could express their desires, fears, and worries more openly (again, the "expressive" quality noted by Cohen).

In discussing their sexual relationships with their husbands, no wife condemned, criticized or even seemed upset about the lack of physical intimacy, perhaps because they were doing so much more nonsexual touching. All but one wife attributed the decrease in sex to the type of cancer and the consequences of the treatment. One female, a patient, did express concern that her husband might be "disgusted by her," although she was experiencing a type of cancer which caused no outward changes in her bodily appearance. The cancer was a threat to her self-esteem, as she related, because she could no longer be active along with her husband, and she "secretly" knew that he thought she was not "normal" nor "acceptable" anymore. The researcher could not determine whether this was, indeed, how her husband felt (he would not address the issue) or if the patient was projecting her own feelings of self-disgust or alienation onto her spouse.

Because human sexuality is an "integral part of one's values, beliefs, personality, interaction pattern and mode of self-expression" (Burkhalter, 1978, p.249), it must be viewed as an important and necessary form of communication in the cancer crisis. The observed decrease of sexual intimacy

but increase in non-sexual contact in couples experiencing cancer should be addressed and investigated, although it is a sensitive and complicated task. Becoming aware of how a change in communication patterns (i.e. from intercourse to handholding) affects and functions for a couple will better help the caregiver to understand how a marital system is dealing with its life-threatening crisis.

Just as couples reported that they were becoming closer as far as their physically comforting each other, many of them reported that the cancer experience had "brought them closer emotionally." Four of the ten couples observed that they were "treating each other better." As one woman said, "I don't criticize him or jump all over him like I used to because, my God, I don't know how much longer I'll have him." The couples related that they were trying to avoid unnecessary conflict, trying to have more patience with each other, and were simply trying to enjoy and share more with each other. This suppression of conflict and cultivation of cohesiveness seemed to function in helping the couples to maintain a "grip" on the emotional nature of the disease as well as to enable them to cope with the uncertainty and disruption caused by the cancer.

Participating in this suppression/cultivation pattern, however, seemed to have ramifications for some of the spouses involved. As one woman said,

> Anymore, I feel like I don't have the right to complain
> about anything. I feel so guilty if I do. I don't want
> to rock the boat and when I see what he's going through,
> I know I just can't argue or complain about anything. But
> sometimes I feel like I'm going crazy!

This characteristic pattern adopted by several of the couples ("I

must not argue; I must have patience.") may discount the range of

emotions that people experience while going through a life-

threatening crisis. Anger, in particular, is the hardest to express

or to accept, yet it is a common reaction during a life-threatening

crisis (Kubler-Ross, 1969). Suppressing and being cohesive may help

the couple to maintain the "status quo," but it may result in the

dyadic partners having repressed emotions and personal frustrations

if they are not able to come to terms with their feelings, both

individually and relationally.

The final general communication characteristic that was observed by

the researcher during her analysis of the subjects' responses

was their use of metaphorical language.

Analogic language (Haley, 1978) allows for expression of

the abstract. Haley notes that unlike language which expresses

a one-to-one relationship,

> meaning is no longer adherent to the referent
> because analogic language deals with symbolism
> or the resemblance of one thing to another. The
> analogic stage consists of a language of imagery
> that creates multiple stimuli and multiple re-
> sponses, which results in flexibility and expres-
> sibility in the language (p.84).

Metaphor is a form of analogic language which attempts to "reproduce

the object (thing, event, relationship) as an image or as a series of

images...." (Angelo, 1981, p.71). In the past, metaphor was studied

primarily as a literary device which writers and poets used to add

mystery and beauty to their creative works. Recently, however, communi-

cation researchers have searched the metaphor as an integral part of

everyday language. Ortony, (1975) posits that the metaphor is an

"essential ingredient of communication" (p.45), a contention he supports

by three theses: the "compact thesis," the "inexpressible thesis" and

the "vividness thesis." Each of these theses, as will be described

and illustrated, relates to the patient's or spouse's need to make sense

out of the crisis. The couples' use of metaphorical language is an

essential process in their comprehension of and communication about their

life-threatening experience. By using metaphorical language to reframe

or transfer their thoughts or experiences into different conceptual domains

or terms, the patient and spouse are able to give heightened or expanded

meaning to their complex thought processes.

The compact thesis. Some metaphors function to give a "compact

version of an event," without the need to describe or spell out all the

details about the event. The compact function of metaphor can be seen

in the following response:

> He (the doctor) walks in like God, telling you you're
> fine, that everything is going well, even though you
> feel like you're going to die at any minute....

Because the patient uses the metaphor "like God," it is not necessary

for him to give a detailed description of how the doctor walked, talked

or acted since these descriptions are already inherent in the choice of

the metaphor. As Ortony observes, the metaphor is "compact" because a "chunk" of unspecified characteristics has been transferred from sender to receiver in only one word--<u>God</u>. The mental image the metaphor builds communicates in a succinct way what the patient was thinking, feeling and observing at the time.

<u>The inexpressible thesis</u>. Ortony believes that metaphors enable people to "make known characteristics that are unnameable." Ortony posits that there are certain things in any language which are inexpressible, and metaphors can function to fill this deficiency.

One of the most difficult interview questions for the couples to answer proved to be the question, "What is it like having cancer?" During analysis of the responses of the patients and spouses, the researcher concluded that the question itself had a metaphorical quality to it, not just because it contained the word <u>like</u>, but because the use of the word <u>cancer</u> seemed to conjure up an image of death in the minds of the respondents. The nonverbal responses of the subjects communicated to the researcher that they were hearing the question as "What is it like to die?", an almost inexpressible thought for some (and perhaps all) people because they do not nor cannot possibly know.

Very few people were able to address this question. Some seemed to be avoiding the use of the word <u>cancer</u> itself (as discussed in the "denial process"); others simply did not know how to put their experience into words, to express what was inexpressible to them. However, one woman who had been asked the question in the initial couple interview, but only remembered to discuss it with the researcher as she was about

to leave from the individual patient interview, related:

> I've been thinking about your question of what it's like
> having cancer. I guess it's like a chapter in my life, a
> chapter in the book of my life. Somebody else is writing
> it for me, and I'm so afraid that when the page is turned,
> there's going to be nothing but blank space, a blank page
> staring at me.

Inherent in this metaphor are feelings of helplessness and loss of control as well as an image of the future (perhaps death) being "nothing-ness" (blank space), which is somehow alive and observing the patient. Inexpressible feelings about death or the unknown are, indeed, expressed through the use of a metaphor.

The Vividness thesis. The last function of metaphor according to Ortony, is to more closely express the"perceived experience because it does not separate individual characteristics, and is therefore more vivid emotionally,sensorially, and cognitively" (Weick, 1979, p.48). The use of vivid imagery, whether intentional or unintentional, encourages "memorability and results in insightful, personal understanding (Ortony, 1975, p.51).

Of the three functions of metaphor, the "vividness" function was the one most noticed by the researcher in her subjects' responses. The patients'and spouses' use of metaphorical words or descriptions in their personal observations about the cancer crisis created images in the mind of this researcher which better enabled her to understand what the respondents were feeling and experiencing, as is illustrated in the following sample responses:

male patient: ....I have succumbed pretty much to what they

(the doctors) have directed.

interviewer: Was that hard to do?

male patient: ....I think if it wasn't such a grave thing....

male patient: I'm fortunate in that I've got good people
down at the store, and they stepped in and
took over and filled in the holes, took over
my work....

female patient: With all those little buggers crawling around
inside and looking for a place to latch on to.
You never know where they're going to show up
next.

wife: I think both of us, if there's a problem, we
want to get there and get it done and taken
care of and be on the way....

husband (patient): Well, let's not have any hidden unveiling or
anything like that. Let's just get the thing
laid out on the table and do what has to be done.

male patient: This damn cancer. It just grabs hold of you
and eats you up.

female patient: I feel it (the loss of her breast) all the time.
Sometimes I won't even be thinking about it and
I get the feeling or impression that there's a
big hole there....

male patient: He, (the doctor) says, "It (the cancer) could

have gotten in the bone marrow and is not

detectable. Also, just like a piece of wood,

carried off into the river and it starts

floating and God knows where it might end up

along the shore somewhere and take ahold and

start growing...."

As can be seen in these responses, metaphor allows one to move closer to

an understanding of an experience because of the vivid and memorable

images it creates and transfers to the listener or observer. And, since

Ortony (1975) concludes that "Imagibility correlates very highly with

learnability" (p.51), the use of metaphor as a language tool can be

viewed as an essential and integral part of the process of sharing meaning

with others.

Chapter 4

DISCUSSION OF RESULTS

In chapter three, "Presentation of Results," the communication
patterns of married couples in this study who were experiencing the
cancer crisis were identified and exemplified. This information
carries further meaning for the communication researcher and the
caregiver. This chapter will address the applications and impli-
cations of this study's results from the perspective of the three
major categories. Included in this discussion of the results will
be a methodological critique of the study's techniques, instruments
and procedures.

Implications and Practical Applications

As was noted at the beginning of this study, the drama of dying
(or experiencing a potentially fatal illness) is usually not played
by a single actor. Because there is a supporting cast, whether that
supporting cast includes the other spouse, the family members or friends,
the drama is fraught with all the "complications and shortcomings" which
are characteristic of the human condition (Shneidman, 1976). The re-
sults of this study exemplify some of the problems that may occur when
person-to-person interaction takes place and, as a consequence, the
results have great potential for practical application and change,
particularly from the standpoint of those who are working with and
caring for these families of crisis. DeVita (in Blumberg, 1980, p.v)
notes that

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Health communicators and planners along with direct care-
givers play an important role in helping cancer patients
and family members cope with the illness. The art of
medicine, by definition, must attend to the quality of
life as well as to its preservation....Whether in re-
mission or receiving treatment, those who are living
with cancer deserve attention to their psychological,
social, and economic needs.

As can be seen in Devita's discussion, helping the cancer patient and
family cope with an illness involves not only the physical care of the
cancer victim, but also the psychosocial care of his or her
marital or familial system. Blumberg (1980, p.1) further elaborates
on the "coping process" used by patients, families and even hospital
personnel during the cancer crisis as

adaption under difficult circumstances, and includes
any means used by cancer patients, their family members,
and caregivers to deal with the psychological and physical
threats imposed by cancer.

She also goes on to note that the emphasis today from both the patient's
and the caregiver's point of view should be living with cancer, not
dying from it. By this she means that concerns about possible death
from the disease should never be minimized, but that often death is
not imminent, that treatments can either extend life or, perhaps cure
the patient. With this in mind, Blumberg contends that "the task of
the health professional then becomes one of assisting patients and
those close to them in living as fully as possible" (p.1). As one
patient succinctly said during a televised interview (A Time To Die:
The Omega Project, CBS, July, 1982) "I'm not dying from this (cancer),
I'm alive and I'll be living until I draw my last breath."

Until recently "living with cancer" could be interpreted from a literary point of view, as preparing for death. But recent advances not only in the medical field but also in the areas of psychosocial care of the patient have made some progress in changing the attitudes of patients and families alike, enhancing the quality of life, not just extending the quantity of days. Viewing cancer as a "chronic illness" instead of a "death sentence" (see Loss of Control, Pattern II, p. 171), and also emphasizing the study of the psychosocial aspects of cancer are two important and necessary steps in helping to restore a family's or patient's equilibrium in the face of loss or change. These two steps can begin with the medical establishment.

Communicating About The Illness With The Physician And Hospital Staff

Information the respondents gave about their communicative experiences with the doctors and other hospital personnel indicate that the patients and families (1) want to be told the truth about their illness, (2) do not want to be given false hope, but do want the doctor to give them as hopeful and as positive a picture as possible, (3) do not want the doctor or staff to hide behind "medical jargon," (4) do want to be able to ask questions and be listened to, and (5) feel ambivalent about being talked to on a feeling level (i.e.,"How are you doing coping with all of this?")probably because few really had an opportunity to do so.

From a medical perspective the results indicate (as the patients and spouses observed) that doctors are seemingly showing a reversal in their past trend of not telling patients the truth about their illness. This change can be seen in the patients' and spouses'

observations concerning their doctors being "open, honest and to the point." All the physicians had a "plan of attack" and most instilled some measure of hope in their patients.

However, the results also imply that medical personnel are unable or choose not to address the feeling or experiential aspect of cancer with the patients, communicating, rather, on an informational or scientific level. As discussed in chapter three (see p.167), there are many contributing factors as to why doctors, nurses and hospital personnel in general avoid feeling level discussions with patients and families. But,what practical implications can be found in the fact that, for whatever reason, the "content level" of communication seems to be the prevalent trend of talking in hospitals or other medical settings?

Although the medical establishment is being trained to heal the sick from a physical perspective, they must also be trained to deal with the "unknown" side of cancer or any illness--the emotional or psychological nature of the disease. Training of medical professionals to deal more effectively with the patient's and family's communicative and emotional levels involves refocusing the educational goals from a purely scientific aspect to a holistic approach, which would view mind and body as inseparable parts in the healing process. By showing as well as teaching health caregivers that feeling level communication can be a positive and healing process instead of a threatening or draining type of interaction, medical educators and communication teachers could give to their students a desire and approach which

these students could then pass along to their future patients. Some re-
search indicates that patients are likely to talk about their illness as
their doctors do (i.e., one can determine a patient's doctor by simply
talking to the patient himself). If this is true, then a healthy pattern
of communicating can begin with the diagnostic interaction itself.
But, before this "healthy pattern" can be used, medical schools or
establishments must incorporate communication training and psycho-
logical education courses into their curriculums and their continuing
educational programs. Training doctors, nurses and technicians, for
example, to do empathic listening or to ask open-ended questions
can only enhance their caregiving abilities. Medical personnel also need to
have more opportunities for therapeutic analysis (i.e., "How did you feel
when you saw your first patient die?"; "How do you view your role....?";
"How do you feel about death?"). More first-hand experiences with
patients and families, who are the best resources for learning about
death and dying, can also help caregivers to be more comfortable and
less fearful in their work with patients and families.

The communication researcher can play an important part in the
education of medical caregivers for s/he can not only provide them
with much needed information and insight about what is happening in the
field (such as this study does), but the researcher can actively partici-
pate in the training of these health care professionals by teaching the
teachers. For example, information elicited from the subjects of this
study implies that doctor/patient communication is a prime area for
"not hearing," not understanding or simply not communicating as well as

one should (doctor or patient). By bringing this to the attention of the medical community, the communication researcher makes them aware that this is a problem area. But, for many communication specialists, their chosen responsibility extends beyond reporting their observations, and, as a consequence, they are able to develop specific training programs to deal with this communication problem--such as training doctors and nurses to repeat information, to cross-check with family members about what they heard, to use language that is understandable, or to generally follow-up on communication interactions with patients (or, as one doctor said to this researcher, "Never take anything for granted when it comes to talking with the patient"). From such training programs can come a more heightened ability to talk with and listen to patients and families.

Besides implementing communication training programs such as those just mentioned, doctors and nurses should be trained to work with the patient and family from a team approach in order to help the doctor, in particular, to shed his/her "God" image and to share the responsibility of the patient's illness with others. Referring patients and families to people specifically trained in communication or psychological counseling can help the doctor (or nurse) to care for the patient more effectively. Getting input about the family system from such people as pastoral care members, hospice volunteers, social workers or psychologists can help the medical caregivers to know what they are dealing with and how they should act and react with the patients and

the family members. The patient, too, could participate in this team

approach by taking the responsibility for his or her own body, illness

and healing process. The patient's participation, along with the

insights and talents of each member of the support team could help all

involved in the healing process to better understand, function and

communicate about the experience. But, the key to this team approach

is working together, which is a pattern of cooperation that should be

expected of doctors or nurses from the very first day they begin their

medical education. This is one of the areas where the communication

researcher and teacher could be instrumental in teaching the medical

teachers to train their students to be supportive and cooperative

instead of competitive and mistrusting.

The Patients' and Spouses' Initial Responses

The patients' and spouses' responses to the cancer diagnosis reflect

the emotional or unacceptable aspect of cancer. Comments show that

reactions do not involve just a fear of death, but a fear of change, a

fear which can be the result of people's responses toward the patient

and spouse (i.e. withdrawal, uneasiness, surprise), or fear which is a

personal consequence of the patient's response towards himself or those

around him (anxiety, depression, disgust, frustration). Cancer, more

than any other disease, can precipitate a whole range of emotions and

reactions in those who are directly or indirectly involved in it.

The need for control over one's personal life as well as the need

for reassurance that one is acceptable or "okay" are paramount in the

lives of marital dyads experiencing cancer. But, how can the caregiver

reassure a patient who is undergoing surgery, chemotherapy or radiation

that she or he is normal or "all right" when all seems to be going badly--the patient is sick, vomiting, losing his or her hair, disfigured, or bedridden. As the local hospice director stated:

> Perhaps "control" is an illusive thing when it comes to
> going through the cancer experience. By necessity,
> people take over for you. What we as caregivers must
> do is to be there to give the patient and family a chance
> to let out their frustrations, anger and concerns. We
> need to be there to reassure him that everything he is
> feeling, no matter what those feelings are, is normal
> and that he has a right to every one of them. (June, 1982).

Being present and being open to therapeutically encourage the patient and family to ventilate their feelings is one important and practical application that can be urged from the information given by the subjects about their personal responses to the cancer experience. However, Blumberg (1980) adds that

> Health care teams can restore at least a portion of that
> (lost) autonomy by helping the patient assume as much re-
> sponsibility for his own care as possible. Patients feel
> less dependent and more productive when they can do even
> simple things....Beyond that, however, they may be more
> willing and able to actually become a part of the health
> care system (pp.24-25).

Another way that health care professionals can help to restore a patient's or family's sense of control and self-esteem is by involving (referring) them with others who are likewise involved in the cancer experience. Programs such as "I Can Cope" or "Make Today Count" provide cancer victims and their families not only with much needed confirmation or affirmation, but they also provide them with an educational background about cancer. This information helps to reduce the fear and myth surrounding cancer.

Medical caregivers can also help to ease patients' sense of isolation or loneliness by visiting them informally both at home (if possible) and in the hospital. Touching, empathic listening, and talking with, not down to, the patient or family can also help them feel acceptable and "human." Those involved in hospice care are now being specifically trained in these areas of verbal and nonverbal communication, but such communication practices need to be common in medical schools of all types. This is something the communication researcher can be instrumental in doing by not only reporting his/her findings, but by seeing that they are used to develop the types of training programs that are found in today's educational hospice programs.

The Adaptive or Coping Responses of the Marital System

The responses of the dyadic partners communicated the importance (1) of educating themselves about the disease, (2) of finding some type of meaning or purpose out of the crisis, whether religious in nature or not, (3) of not being emotional about their situation, (4) of being inwardly strong and outwardly positive and hopeful, (5) of using various types or levels of denial, and (6) of having some type of relational homeostatic functioning (maintaining the status quo). The marriage partners either implicitly or explicitly stated that they collaborate on most of the coping processes, although finding a meaning or seeking information can sometimes be an individual effort.

Mutually pretending that everything is "all right" or that the outcome of the disease will be positive enables the marriage partners to deal with the threat of loss or change that the cancer has

precipitated. Denial, whether it takes the mutual pretense form or any of the other forms that were discussed in chapter three, is difficult for others outside the marriage system to handle. Nurses, doctors, even fellow hospice volunteers with whom the researcher has worked have talked to her about their inability or discomfort in dealing with patients (and spouses) who are denying. They can recognize denial, but don't know how to handle it, so, many times they simply ignore or withdraw from the patient.

The study's findings have helped this researcher to understand that (1) where there is denial, there is some level of knowledge or acceptance of the possible outcome of the disease, (2) denial not only provides the patient with time to accept the full impact of a cancer diagnosis, but it also functions to help diminish the threat of the loss of a significant relationship; and (3) denial gives hope, a necessary ingredient for cure. Responses of the patients and spouses indicate that caregivers should not feed denial, yet they should not force a person to accept information which he chooses not to (whether through not hearing, minimizing, negating, and so forth). When denial is not collaborative, that is, when only one marriage partner is suppressing or denying, then it is the caregiver's responsibility to provide therapeutic outlets for either spouse to talk or express his or her feelings, if they so choose, without upsetting the homeostatic balance of the marriage system. And, caregivers of all types must be cognizant of the fact that there is no "perfect acceptance" of a cancer

diagnosis (just as there is no "perfect death"). The patient and family may equivocate between denial and acceptance throughout the duration of the disease.

If a family is to successfully cope with the cancer crisis, caregivers must also provide the patient and family with opportunities, materials and human resources with which to educate themselves about their disease. This important application, which is justified by the findings, can be implemented by involving patients and families in support groups, referring them to written literature in the field (again stressing the importance and application of a study such as this), or directing them to other individuals whose experiences are similar to their own.

However information is obtained, the caregiver must give attention to the processing of that information through the dyadic system. If, for example, one spouse is doing the listening and conveying of information for the other spouse, as the findings indicate, then the doctor or nurse should follow up on that filtering process to find out whether the information being communicated is accurate and whether the information processing system itself is detrimental or helpful to the patient's or spouse's coping processes. If a cross-check proves that the patient or spouse is not getting the full information, then this can be alleviated by opening up new communication channels (i.e., talking to the patient alone, having the nurse provide more written literature on the topic of cancer, having a hospice volunteer talk informally to the family). If, however, the doctor or nurse concludes that the information processing

system is functioning to maintain denial or homeostasis (because the caregivers have been trained to be aware of these functions), then the medical professional should simply anticipate the couple's need for information and offer it to them through any and all means possible, including answering all questions which the patient and spouse might have.

Referring patients and family members to pastoral care or ministerial members is another means by which the caregiver can help them make sense out of their experience. As the findings suggest, faith means a great deal to many people involved in the cancer crisis, and spiritual support can provide much comfort and solace during difficult times. But, for some the cancer crisis may push their faith to the limit as they see someone they love in pain, or if they cannot answer the question "Why me? I've lived a good life and have been a faithful person?" The patient or spouse may displace their anger at God onto more acceptable sources, such as the medical staff or the family members. To handle this possible displacement, the caregiver should again utilize the team approach, referring patients and spouses to pastoral care members or therapists. Or the nurse, doctor or other caregiver could simply provide the patient and spouse with opportunities to vent their anger without fear of recrimination or disapproval. Patients and spouses have a right to be angry (or fearful, and so forth), and caregivers must not forget this or ignore it. Again, training in empathic listening or conflict management would help the caregiver to better understand, accept and handle

angry confrontations or outbursts from patients and spouses, while also enabling them to deal with their own personal responses to and feelings about those expressions of anger.

The most important implication learned from how couples cope is that they need to have the opportunity to choose the way they wish to cope and the opportunity to change those patterns which they find are not working for them. The findings in this study also indicate that the quality of their life as the dyadic partners "live" with their cancer crisis is of utmost importance and consideration to all those involved in their physical and emotional care. Although the quality of that life should be determined by the couple itself, many of the means to achieve this quality (not simply a quantity of days) can be provided by the caregiver and the communication researcher, working together to establish better training and education programs as well as increased sensitivity and heightened awareness of the needs of cancer victims and their families.

Integration With Existing Literature

As discussed in chapter one, there is an abundance of books written in the area of death and dying, but little research written about the family system and how it copes and communicates about the illness. What is written is insightful as well as instructive, but much of the research is not personalized enough to meet the individual needs of a patient or family experiencing a life-threatening crisis.

The present field study, which involved personally observing, studying and listening to couples as they progressed through the

cancer experience will add to the very limited body of literature written about the communication and coping processes of families in crisis. The study's results reflect the complexity of these processes and how they function for those involved.

As a caregiver or as a communication researcher, one cannot adequately understand or appreciate what happens in families who suddenly are faced with change and/or possible loss without first listening to (or at least reading) personal accounts of what the experience is like for them. In this field of research, the people undergoing the life and death crisis are the experts, not the field worker, nurses or doctors. Those who are "living with cancer" are those who can truly talk about it with insight, sensitivity and newly-found awareness. It is the job of the caregiver and researcher to be open to what they are saying and to adequately reflect their message and meaning through verbal or printed word. It is hoped that this study begins to do that.

Implications For Future Research

As the researcher progressed through her study, different areas of possible inquiry and research surfaced when she determined what she did <u>not</u> find. First, because of the noticeable differences in responses which came from the young couple in the study compared to the partners who had married for a much longer period of time ("Mature and enduring relationships," as Leiber calls them. See p.70 for discussion.),the researcher concluded that a much-needed companion study for this one would be one that researched young or newly-married couples who are

experiencing the cancer crisis. The life-cycle stage of a person or a marriage can be a potential indicator for the types of responses that are made, and a study of younger couples would not only enhance this one, but would reflect the differences the age of the individuals or the length of the marriage may make on the type of responses given.

Second, future qualitative studies of marriages undergoing life-threatening crises could implement more devices and scales, such as satisfaction measures, which would give information about the reported state of the marriage. For instance, while exploring the coping and communicating processes of the dyadic partners, the communication re-searcher could gain additional and valuable information about the marriage system itself by giving the couple pencil and paper scales which would, for example, help them evaluate and report their level of satisfaction with the marriage or their general, pre-illness ways of handling conflict. This information could then help the researcher to better understand and identify the marital system structure and function-ing processes. Developing correlational indices from the information gathered from these measures (i.e. "If the couple is x, then they will usually cope by doing y") can have great potential for guiding doctors, nurses, and other caregivers who do not have training or time to do in-depth counseling or research into the patients and families they are dealing with, but must make on-the-spot judgments about family function-ing and potential coping ability, based on immediate behavioral or verbal responses.

Another need for future research that this study engendered is in

the area of the patient's and spouse's use of metaphorical language.

A suggested study of the metaphor's function for families of crisis could tap three areas of heuristic value: (1) metaphors being used and responded to on the same metaphorical level during conversations with patients and families (noting what the symbolic language is communicating and how it functions for the communication participants); (2) metaphors (simple or extended) or metaphorical stories, written or verbalized specifically to illustrate how a patient or family member is feeling or what s/he is experiencing (i.e., "Write or tell me what this experience would be like if it were a television program, soap opera, cartoon, medical show. What would the story line be? How would you describe your part?"); and, (3) an analysis by judges of audio tapes of patients and families responding to interview questions about their cancer experience. Metaphorical use (whether intentional or unintentional) would be the main focus of the judges' analyses, but they would also try to determine the function of the metaphor for those involved. Any research of this type which studies the actual language being used by the patients, families, and even hospital personnel would provide valuable insight about their experiential worlds and their systems' structure and functioning, as well as suggesting treatment areas and points of therapeutic intervention.

A fourth area of concern that would be ripe for research, particularly utilizing a team approach, is to study an entire family system (or many family systems, depending on time and person-power), including not only the immediate family of the patient, but also his or her

relatives (distant or close). This study provided the groundwork for a possible family research project as just described. But, what the researcher did not find out, except in two different cases, was how the children felt about the cancer experience. The two times that the interviewer was able to talk with the children of the respondents, the informal cross-checking process added much insight and discovery about the dyadic partners' relationship and the general family structure. Her limited experience with interviewing other members of the family system besides the husband and wife made the researcher realize the potential value for studying all members of a family system.

Another factor which could be included for consideration in the above mentioned study is that of the stereotypical differences which might occur in the family members' responses. The study indicated that men and women talk differently about their cancer crisis or even about their everyday lives. Although the researcher made no conclusive statements about what she observed, she did note that women seemed to be able to communicate more on a feeling level, both verbally and non-verbally, than did men. The differences detected in communication processes when the patient was female or male are worth noting and studying, particularly because of the effect that these differences could have on the entire family system.

A final and much-needed extension of this research project would be to do a comparative analysis of married couples who have been determined (by some type of assessment measure) to be low or high in emotional expression to see how each type copes with crises, particularly

life-threatening crises. This study could also assess if feeling-level communication does function, as this researcher believes it does, to sustain energy and help the couple to adjust to their situation in a healthier, easier way (as compared to suppressing or mutually pretending, for example). Specific studies in this area could possibly determine the value of talking on a feeling level about one's feelings.

Critique of the Study

As was noted in chapter two, the main qualitative techniques used in this study were participant observation and interviewing, with field note analysis and tape transcription. This researcher, after completing the qualitative process, feels very satisfied with the use of the interview to explore the experiential worlds of the patient and spouse. Because so many of the couples related that they felt "overwhelmed" or "out of control," the researcher felt that the interview situation provided the couples with a legal, or "acceptable" way of ventilating their feelings, as well as providing them with an opportunity to be listened to. Someone outside the medical profession or outside of their marital, family and social systems was looking to them for answers and insight about their experiences. For some, the interview session became the first time they really "talked" or "listened" to each other about the disease in general or their feelings in particular. Even though, as already discussed, there was a tendency for the dyadic partners to "be strong or unemotional" in front of each other, the individual interviews allowed many of the respondents to express their true feelings, fears and frustrations without the threat of upsetting

the relational homeostatic balance.

After the researcher got over her initial nervousness about inter-viewing the couples, she had little or no difficulty in entering into their lives. She especially enjoyed and appreciated the interview format of talking to dyadic partners together, then talking to them separately, a process which she felt they appreciated, too. Any "fear of the unknown" they may have encountered in the first sessions could be minimized because of the presence of the other spouse.

Using a tape recorder proved to be a great asset in helping the researcher write up what had transpired during the interview. She did, however, have some mechanical problems with its use during several of the sessions, but had heeded Lofland's (1971) advice about taking sparse notes "just in case the tape recorder breaks down." The sub-jects' responses to having a tape recorder in the sessions was in-structive to the researcher. Although she assured and reassured the couples that the tapes were private and that no one but she would listen to them, some of the most intimate informational responses that were given were said when the tape recorder was off, which led the researcher to conclude that her subjects did not fully accept the explanation of confidentiality.

In one case, a male respondent turned the tape recorder off him-self, so he could tell the interviewer about some business venture he was into. He then turned the tape recorder on and continued on another subject. On the other hand, several times during the sessions, the recorder clicked off (the end of side one) and the respondents stopped

in mid-sentence and would not start again until the tape was turned over and was going. It was as if they wanted every word preserved on tape. All in all, the tape recorder was very useful, but it appears that the respondents, for the most part, were aware that it was being used, which may have been due to procedures.

The value of the interview, however, cannot and should not be underestimated. As Johnson (1979, see p.94) noted in her study of the sexual concerns of patients and spouses, using the interview technique provided her with an opportunity to have "intense and complex" communication with her subjects, while also precipitating a relationship with some of them that continued after the interviewing was done.

The interview methodology also gave this researcher opportunities to participate in intense and complex communicative interactions with her respondents which, in many cases, developed into relationships that grew beyond the researcher and subject roles. In addition to the therapeutic value that the interview technique had, the information it yielded proved to be insightful, instructive and accurate (when the researcher compared it to other first-person or literary accounts). The interviewing method provided the researcher with sensitive tools to study a sensitive and personal area--a life-threatening experience, and the heuristic value of the information she found by using this methodology only reinforced her opinion (as discussed in chapter two) that qualitative methods such as interviewing or participant observation are important and valuable tools by which researchers can study and understand the complexities of the human condition.

Threats To Reliability

The constant comparative method helped the researcher to become aware of any inconsistencies in results derived from the different techniques or in differences in behavioral and verbal responses to the pre-chosen questions. Meeting with her adviser to cross-check her use of the constant comparative method also proved helpful in enabling the researcher to effectively implement the approach as well as to tap the constant comparative method's full potential for usefulness.

The effectiveness of the final reliability check that the researcher implemented in the study, the use of two judges to do inductive and deductive testing of the results, can be seen in the high percentage of researcher/Judge A, Judge B reliability (83-84%). This researcher was very pleased not only with this high percentage or reliability, but also with the enhancing or clarifying quality of the judges' observations and descriptions.

Threats To Internal Validity

The following potential threats to internal validity (see pp.122-126 for discussion) did materialize in the study and did prove to be a problem for the researcher.

Setting. In two situations, it was necessary for the researcher to interview her subjects (in one case a spouse; in the other situation both the patient and spouse) within a hospital or waiting room settinr, and in both instances, there were many disruptions (nurses, the other occupant in the double room, television, visitors). Although there were many times that everything was quiet, the researcher was always

aware that she and the patient or spouse were not alone, that complete privacy was not going to be possible for these interview sessions. Consequently, the researcher did feel that her respondents may have wanted to say more, but were unable to because of the lack of privacy. This was something she could not remedy.

Bias. Throughout the interviewing process, this researcher questioned her role and its effect on her respondents. She constantly asked herself whether her rapport with her subjects was too much or too little, yet, the researcher syndrome of "going native" was experienced, but not for the contributing factors mentioned in chapter two (see pp.124-126).

While in the midst of her interviewing process, the researcher's father had a heart attack and subsequent bypass surgery. After going through the surgical and recovery process with her father, the researcher proceeded to start her interviewing again, but upon listening to her tapes (again using the constant comparative approach), she noticed that she was talking more than in preceding interview sessions and was "over-identifying" and overreacting to some of the responses the couples were giving. Because the researcher had been experiencing, first-hand, the loss of control and the "God-images" of the doctors that her respondents had been discussing, she wanted to (without consciously knowing that she was doing this) cathartically share these experiences with her subjects. This did precipitate some in-depth, "comparative" types of discussions from her subjects ("Oh, yes! I know exactly how your father must have felt. When I was in the hospital....")

When the researcher concluded that the project was suffering from the "going native" syndrome, she (1) discussed the matter with her adviser, (2) reminded herself constantly throughout future interview sessions of the tendency, and (3) listened to and analyzed future interview tapes with the "going native" issue in mind. Being aware of what she was doing (and why she was doing it) enabled the researcher to work on solving her overidentification problem.

The "going native" problem, as her adviser reminded her, did, however, have one important advantage for the researcher. The insight she received in personally experiencing a life or death crisis with a family member proved to be a valuable asset in her development of future interview questions for the study. As a consequence, she felt the study's categorical results truly did reflect the life-threatening experiences of the subjects.

Threats To External Validity

The following threats to external validity occurred in the study. Generalizability is considered in light of these factors.

Reactivity of outcome assessment. As noted at the beginning of this section, the researcher felt that, for the most part, her subjects were aware of the tape recording technique being used. The extent to which this awareness hurt the overall research process was considered to be minimal in that the researcher was able to interview her subjects both with and without taping them, thus being able to compare the results while also being able to use the richness of both interviewing atmospheres--formal and informal.

The subjects appeared to feel comfortable and non-threatened with the researcher, although some degree of reactivity to the interviewer could not be eliminated from the sessions. At various moments, the researcher found herself asking the question, "I wonder if they (the couples) are describing what really happened or if they are describing an 'ideal' situation which they think I may want to hear?" An excellent cross-check in considering this question proved to the the interview format itself (using the constant comparative approach). Interviewing the couple together, then waiting for a period of time and interviewing them individually, proved to be an effective test of the consistency of the respondents' answers.

Selection. Because an availability sample was used, the resulting selection of respondents did not allow the researcher to make any conclusions about differences in responses because of cultural or religious background or years married. The results have potential generalizability to all types of people experiencing the cancer crisis, however. The literary support the results have and the positive response the study's information has precipitated from the various people the research has used as cross-checks (doctors, nurses, hospice director, hospice group and adviser) attest to its validity.

Summary

This study showed that couples experiencing the cancer crisis communicate about and cope with the life-threatening experience in ways that will contribute to the maintenance of their marital systems functioning. After receiving the cancer diagnosis, the patient and spouse find

themselves experiencing a whole range of emotions, chief among them being the fear of unacceptability and the sense of lost control.

To combat these feelings and to maintain personal and dyadic equilibrium, the couples use various types of coping and communicating patterns, including information gathering and processing, rationalization (either religiously-based or otherwise), humor, denial, suppression and avoidance, mutual pretense, talking only on a content level, using outside human resources for support and, finally, opening up new verbal and nonverbal communication channels with each other.

One of the most significant findings of the study, in this researcher's opinion, is how couples collaborate in their avoidance of feeling level communication about the cancer experience. Factors contributing to this pattern include the dyadic partners' need to maintain the status quo, their mutual desire to protect each other, and their personal need to keep a positive, hopeful attitude about the situation. But, inherent in this pattern is the attitude that expressive of emotional conversation is something which can be energy-draining instead of energy-sustaining. The male respondents in this study, in particular, seemed to fear or be uncomfortable (even disgusted) with feeling level communication for themselves, but they seemed to be less judgmental about their wives being emotional. When emotional expression did occur, however, it had to be done in an acceptable way (mixed messages, outside sources, "controlled" tears, anger or expressions of fear, private grieving).

This and the other findings of the study have several implications

for the communication researcher as well as the health caregiver. For the researcher, the results indicate the need for more study of and exploration into communication during crises and how different communication patterns function for those involved. If content-level talking seems to be the type of communication level that is preferred by the medical establishment as well as the cancer victims and their families, what does this indicate about the state of health of the family or medical system? The researcher needs to study whether the avoidance of feeling-level communication is helping or hindering the coping processes of those involved. The communication researcher also not only needs to understand and identify the type of communication patterns that are occurring in the families of crises, but s/he needs to identify potential areas of communication breakdown in order to recommend points of entry for therapeutic intervention.

The findings of the study indicate that the caregiver must view the patient and family as a system undergoing a crisis, not an individual experiencing an illness. The caregiver must give attention to all aspects of psychosocial care of the patient and family, and when or if she or he feels incapable of dealing with the complex communicative or coping responses of the cancer victim and family, then the caregiver should use a team approach and be willing to refer those in his or her care to people who are trained in dealing with the psychological or therapeutic aspects of a life-threatening crisis. The caregiver also needs to evaluate and come to terms with his or her own feelings about the death and dying process before s/he can effectively minister to those

in need.

This study attests to the fact that information about families facing the possible death of one of their members is still needed; it also shows that more specific training, both on and off the job, must be given to caregivers so they can deal with life and death situations. Finally, it again gives witness to how complex and intricate the human response is to the possibility of change, loss or death. Understanding how that response functions for the individual or the relationship is the responsibility of the researcher and the caregiver in order that they can effectively study and thus help those involved in the life-threatening crisis.

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Appendix A

Date _____

Facesheet

Name:

Ages: _____ Husband _____ Wife   Number of Children: _____

Occupations: Wife: Ages:

              Husband:

Marriage: First _____   Religion: Husband:

          Second _____   Wife:

          Third _____   Patient: Wife: _____

          Fourth _____   Husband ___

Years Married: _____   Date of Diagnosis: _____

Nationality: Husband: Type of cancer:

           Wife:

Educational
Background: _____

<u>Appendix B</u>

Name: _____

Date: _____

<u>Couple Interview Schedule</u>

Perceptions
of Personal
Actions/
Reactions

1) Who first described your illness to you?

How did the doctor describe your situation to you?
How did s/he describe the <u>severity</u>?
What did he say the <u>diagnosis was</u>?
How did he tell you?
What did he do after he told you?

2) How did you react? What did you do after the doctor talked to you?

3) (If appropriate) To Spouse: Since you weren't with your husband/wife, how were you told?

Who told you?
What were you told about his/her condition?
How did you react?
What did you do after you were told?

4) How did you first talk about your situation with each other?

What did you say to each other?
How were you acting?
Do you feel you were both understanding the situation in the same way? Explain.
How were you able to express your feelings with each other, or were you able to? Explain.
What would you have liked to do instead?

5) What was the course of treatment prescribed?

How did you and your doctor make a decision about this?
As time has progressed, have you and your spouse and doctor been making these decisions in the same way? Explain.
How do you feel about that?

Perceptions
of Family/
Friends'
Communication

6) How did your family react to the news of the illness?

Did they react as you expected them to? Explain.
What were they told?
By whom? How were they told?
How did you discuss/decide on how they would be told?

7) How did your friends react upon hearing of your diagnosis?

How were they told? By whom?
How did they talk to you/your spouse about your situation?
How did they act?
Did you and your wife/husband talk about this? Explain.
How have your friends communicated with you since then about your illness?

8) Did you and your husband/wife tell anyone else about your illness? If so, whom?

What were they told?
How did you decide this?

Perceptions
of Medical
Staff/Patient
Communication

9) How did the hospital staff, such as _____, care for you, your husband or wife)?

How do/did they talk to you about your cancer?
How do/did they talk to you about your spouse's cancer?
What do/did they say?
How do/did they act/react around you?
How would you describe the care they are giving/gave you?

10) (if appropriate) Since you are taking chemotherapy, radiation, and/or cobalt, how are you being treated by the staff?

How do the staff members talk to you about your/your spouse's illness.
When you are in the waiting room, what do the other patients and families talk about?
Do you talk to other patients or families about your/ your spouse's illness? If so, what do you talk about?
What seem to be their concerns, frustrations, fears?

Perceptions
of changes

11) What is it like having cancer? Paint me a picture,
or describe a day, moment, event which in your mind
tells someone like me what it's like to go through
the cancer experience. Or, even create a scene which
would show me what you/your spouse go through having
this illness.

12) How has your illness changed your life?

Describe changes, anything you do differently.
Have any family routines changed? If so, how?
How would you describe your roles in the family
before your illness?
Has the illness changed that? If so, how?
How do you make decisions now?
Is this any different from the way you both used to?
If so, how?
How do you look at life now?
Is this different than when you/your spouse didn't
have cancer? How?
How has this illness changed your relationship?

13) How do you talk about these changes with each other?

14) What do you remember as being times of difficulty or
crises for you and your spouse?

How did you react?
If those hard times happened now, how do you think
you'd react?

Coping

15) How are you coping with your/your spouse's illness?

16) Are there times when you feel angry or frustrated?
Would you describe what's going on?

Talk about what you feel and think during those times?
What do you do when you feel this way?

17) How do you both talk about your illness?

How do you feel about the outcome?
What are your concerns?
What do you worry about?
How do you comfort each other?

Sources of   18) What have you felt to be the most helpful responses?
Support/
Helpful   Could you talk more about that?
Responses

19) What have been the least helpful/irritating responses?

20) What types of support do you feel you/your spouse
     need(s) to help you/him/her through this?

     Do you feel you are receiving these types of support?
     Explain.

21) Could you tell me anything more about this experience
     you are going through?

     Do you have anything you would like to add about how
     your communication has been with each other lately?
     Is there anything else that you can think of that will
     help me understand what your life has been like
     since _____(Time)_____ , when your/yours spouse's cancer
     was discovered? Is there anything you can tell me that
     will help me see what you're going through?

<u>Appendix C</u>

Name: _____

Date: _____

<u>Patient/Spouse Interview Schedule</u>

Personal   1) Do you want to tell me any more about your personal
reactions to your/your spouse's illness? Explain.

Meta-   2) You told me how you and your spouse were told about the
communication   cancer. How do you think your spouse felt at that time?

What did s/he do to make you think that?
What did s/he say to you?
Do you think s/he understood what the doctor (or
whomever) was saying? Explain.
Do you feel your spouse had the same understanding
of the situation as you? Explain.

                    3) What do you think your spouse thinks about the situation?

How is s/he acting/reacting?
How is s/he coping?
How do you talk about it?
Describe times that are most frustrating for him/her.
How are you able to share those times with him/her?

If the roles were reversed and you/your spouse had
the illness, how do you think you/s/he would act or react?
How would things be different?

Perceptions   4) What are your concerns about ___(name)___?
of Relationship

How do you fit into those concerns?
What do you think his/her concerns about you are?
How does s/he let you know this?
How do you talk about it?

                    5) Since we're talking about ___(name)___, what was it like with
your relationship before your illness?

Describe a typical event which would give me a picture
of your life together.
How did you meet?
What first attracted you to him/her?

Changes   6) How is life different for you and your spouse now?

                      Are there things you and your spouse used to talk
                      about but can't now? You want to talk about that?
                      How does that make you feel?

                   7) How do people react or talk to you/your spouse now
                      that you/s/he has cancer?

                      Do you see any other differences in people's approach
                      to you? You want to talk about that?
                      Is there anything different going on in your family
                      since the illness? If so, explain.
                      What about your marriage--do you see any differences
                      there? Explain.
                      How do you get things done--decisions, chores, things
                      like that? Is this any different than before you/
                      your spouse got cancer?
                      How are decisions getting made with your doctor?
                      Would you change anything there?
                      How have you and the doctor been talking lately?

Personal   8) What is the most difficult thing for you to handle?
Descriptions
(Positive/Negative) What do you do?
 Influences   How does that make you feel?
                      How are you able to share that with your spouse?
                      What is the most difficult thing for your spouse
                      to handle?
                      What does s/he do? How do you talk about it with him/her?

                   9) Are there days when your/your spouse's pain seems
                      to be worse?
                      Describe what is going on on those days.

                      How do you talk about that with your spouse?

                  10) What is the most positive thing that has come out of
                      this experience for you? For your spouse?

11) In going through this experience, what has been the most helpful to you? Your spouse?

What has bothered you/your spouse the most?
How are you able to share this with him/her?

Meta-
communication

12) How do you think your spouse feels about the outcome of your/his/her illness?

How do you feel about it?
Do you talk about it with him/her? If so, how?

Mixed
Messages

13) Is there anybody in your world whom you think is saying one thing, but meaning something else?

What do they say, do?
How do they act?
How does that make you feel?
Do you think you can change the situation? If so, how?
How are you able to share this with your spouse?

Coping
Mechanisms

14) What has helped you get through some of the hard times in your life?

Describe or give me an example.
What has helped your spouse?
What has helped your family?

Self-
Esteem

15) What have you learned about yourself from going through this experience?

How do you feel about yourself?
Is this any different from when you didn't have cancer?
Is this any different from when your husband/wife didn't have cancer?
How do you think your spouse feels about her/himself from going through this experience?
How do you talk about this with each other?

Coalitions 16) Whom do you feel closest to right now? Could you talk about that?

17) Have you talked with anyone in particular about your situation? What do you say?

How have they helped you?

Final Comment 18) Can you tell me anything more about how you and your spouse are talking with each other? Is there anything that you'd like to tell him/her, but haven't or can't? Explain.
Is there anything else that you can think of that will help me understand what your life has been like since the cancer was diagnosed?

Cross-check/
Follow-up
Questions: