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Abstract

THE FAMILY CANCER EXPERIENCE:
A QUALITATIVE STUDY OF FAMILIES IN WHICH
AN ADULT MEMBER IS LIVING WITH CANCER

This study was designed to elicit the perceptions of families who are experiencing cancer in one of their adult members for the purpose of describing and explaining psychosocial aspects of the cancer experience from a family perspective. The method used in conducting this study was the phenomenological paradigm of qualitative research.

Data were collected through a series of interviews with eight families comprised of a total of seventeen members. The eight cancer-patient members were all between the ages of 59 and 66. The initial interviews were loosely guided by the research questions, and addressed the families' perceptions of the impact of cancer upon psychosocial aspects of their everyday lives. The data were comprised of the accounts given by families in these interviews. Constant comparative analysis was employed throughout the data collection phase to permit analytic material to guide and focus the process of constructing accounts.

The families described their everyday lives with cancer as being normal lives notwithstanding a number of changes directly associated with having cancer. They perceived themselves to have minimized the impact of change through a number of consciously-chosen strategic approaches. They explained the normalcy of their experiences in terms of the successfulness of these strategic approaches. Further, they explained the success of their strategies in terms of the relationship of these strategies to their family self-concept and philosophy.
The data revealed the capacity of older families to modify and make sense of their cancer experiences. By applying attitudes which conformed to their histories and philosophies, they minimized changes in everyday life, created support networks, facilitated the quality of their medical care, and generated hope.

In terms of nursing practice, these findings reinforce the value of incorporating family beliefs and attitudes into all phases of the nursing process. They therefore strengthen the argument for evaluating effective and ineffective coping on an individual basis rather than according to commonly-held assumptions. Implications for future nursing research include further exploration of selected themes that emerged from the study, and expansion of the body of knowledge about family functioning to include the family's perspective.
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Chapter 1

Introduction

Background to the Problem and Purpose

Nearly one hundred thousand Canadians will be diagnosed with cancer this year. In five years time, at least fifty percent of those people will still be alive. As cancer treatment improves longevity and reduces mortality, more and more Canadian families will be living with cancer in one of their members (MacDonald, 1979; Rothwell, 1983). In fact, two out of three families at some point in their history will encounter this experience (Brody, 1977).

The perception that cancer is a life-threatening illness poses one set of psychological forces upon the experience. "Whether the threat of death is real or imaginary, tremendous emotional strain is placed on the patient and on his family" (Smith, 1975, p. 39). Cancer may also imply pain, disfigurement, and the uncertainty of recurrence. "Few other illnesses combine so tragically the wearing qualities of a long illness with the tearing qualities of an acute one" (Barckley, 1967, p. 278).

Attention to emotional needs is a relatively recent addition to standard cancer care (Hartman, 1980). The psychosocial implications of having cancer are addressed in an abundance of recent literature about cancer. Miller, Denner, and Richardson (1976) in their review of research conclude that "it is likely that all individuals who are diagnosed as having cancer have some sociological and psychological problems in coping with the situation" (p. 161). Creech (1975) compares the social implications of having cancer today with the historic plight of the leper. He argues that these social ramifications contribute to the unique psychological problems found in cancer patients and their families.
Recent trends in nursing and health care emphasize the belief that patients cannot be viewed as isolated individuals, since they influence and are influenced by families (Geary, 1979). Bahnson defines the family in a manner that illustrates this interrelationship:

The family is not a conglomeration of individuals who happen to live together. It is an intricate emotional and communicational as well as cognitive system, in which changes in one part of the system immediately dictate reorganization in the remainder. (1975, p. 306).

The psychosocial impact of cancer upon families is believed to be as unique and as devastating as it is upon individuals (Nelson, 1973; Ross, 1979; Sheldon, Ryser & Krant, 1970; Wellisch, Mosher & Van Scoy, 1978). The implications of cancer may affect families to a greater degree than they affect the individual patient, particularly if the family is without health care system supports available to the patient (American Cancer Society, 1975; Speese-Owens, 1981). As one oncology nursing leader states, "cancer is a social illness which takes its toll on the entire family unit" (Van Scoy-Mosher, 1978, p. 22).

The family as a critical target for nursing, a notion substantiated by several nursing theorists (Green, 1980; Johnson & Norby, 1981; Welch, 1981), contrasts sharply with the traditional nursing perspective of family as emotional support system for the individual with cancer (Giacquinta, 1977; U.S. Department of Health and Human Services, 1980). This shift in perspective carries with it a requisite shift in implications for nursing practice in relation to such families.

Bahnson (1975) emphasizes the notion that health care professionals must attempt to discover the perceived or existential meaning of the disease and its implications for individuals and families.
From the point of view of psychologic management, it is crucial to learn exactly what the disease means to a particular person; which dreams, images, self concepts, goals, hopes, it thwarts or modifies; and what are the main implications for this particular patient and his family system of the changes in him and in the system that result from the disease process. (p. 293).

The values underlying this demand are consistent with the emerging emphasis on the nurse's role to provide holistic care to patients and families (Welch, Follo & Nelson, 1982). Holistic cancer nursing care relies upon an understanding or appreciation for the experience the family is undergoing (Wegmann & Ogrinc, 1981). It requires that nursing address the issue of "what families grapple with as they experience having a member with cancer" (Green, 1980, p. 21).

While a literature review reveals numerous theoretical assumptions about what the family cancer experience entails, research has not yet established the degree to which theory does or does not explain the nature of the phenomenon as experienced by families. The most obvious data source, the families themselves, is largely untapped.

Statement of the Problem and Purpose

The general problem to which this study is addressed is the lack of knowledge about the family cancer experience as perceived and articulated by the families themselves. Current cancer care trends demand that families as well as patients be considered. Nursing's holistic focus is consistent with this philosophical stance. In order to predict and prevent family problems, and to plan care that includes and deals with family issues, nurses must develop some understanding of the nature of the family experience.
Although considerable theory and opinion are available in the published lay and professional literature, there is little evidence as to the extent to which such theories provide accurate and realistic explanations for what families do experience in relation to cancer in their midst. The purpose of this study is, therefore, to describe and explain psychosocial aspects of the family cancer experience as perceived and articulated by families wherein an adult member is living with cancer. Selected areas within this multifaceted and complex experience will be used as foci for exploring the phenomenon. Therefore, the specific questions that direct this study are as follows:

1. What is it like for a family to have an adult member with cancer?
2. What aspects of the cancer experience have an effect upon a family's everyday life?
3. How are family role responsibilities affected by the experience of cancer?
4. What is the relationship, if any, between family values, attitudes, or philosophies and the family's cancer experience?
5. What is it like for families to talk about their experience of living with cancer?

Definition of terms

Cancer: the proliferation of malignant cells that have the capacity for invasion of normal tissues.

Individual with Cancer (Cancer Patient): for the purpose of this study, an individual over the age of eighteen who has been diagnosed with a cancer at least two months prior to participating in the study, and who is not, in the opinion of his or her physician, in the terminal stages of that illness.
Family: for the purpose of this study, the group of persons identified by the individual with cancer as being significant to him or her, regardless of factors such as kinship ties or common household.

Cancer Experience: reactions to the presence of cancer, and its ramifications, within the context of everyday life.

Context of Everyday Life: the family's daily living, including events, routines, roles, and relationships.

Introduction to this study's methodology

The methodology for this study is qualitative and relies on phenomenological theory as its framework. Qualitative and quantitative approaches originate from disparate views of social reality and seek to generate essentially different types of knowledge. Thus procedures, notation systems, and even values are correspondingly different for each research approach (Schwartz & Jacobs, 1979). Quantitative methodologies assume that "the study of observable deeds and expressed words is adequate to produce knowledge about man and his natural world" (Rist, 1979, p. 19). The phenomenological paradigm of qualitative research serves as a tool for rationalizing certain species of knowledge that are not within the naturalistic traditions of science (Davis, 1978). This approach assumes that "there is value to an analysis of both the inner experience and outer behavior of a subject as viewed by both the researcher and the participants (Rist, 1979, p. 19).

The role required of the researcher in the phenomenological paradigm of qualitative methodology is that of entering into the process being studied for the purpose of interpreting it as it appears to the people engaged (Davis, 1978). "Grounded events," those experiences shared and
understood by participants and researcher, provide the data from which concepts and hypotheses emerge throughout the research process (Rist, 1979). From this data, and in relation to this data, "grounded substantive theory" may be generated (Lindemann, 1974, p. 106).

In qualitative research, the principles of representative sampling do not apply. Theoretical sampling is the process by which "informants" are selected by virtue of their competency to answer the research questions (Spradley, 1979). The usual notions of reliability and validity are also inapplicable to qualitative methodology. Rather, the criteria by which the research may be judged are the richness of the data and the credibility of the concepts and theories developed from them (Diers, 1979).

Assumptions and Limitations

The researcher approached this study with the assumption that there are psychosocial implications associated with having an adult member with cancer in a family. She further assumed that these implications have an impact upon the everyday life of the family, and that the family unit can express them in a different voice than could individual family members. In addition, she assumed that the information shared by a family group is an accurate reporting of its perception of reality. Her final assumption was that an understanding of what this experience is like for families could be ascertained through phenomenological research methods.

The depth and richness of the data for this study are limited by the time constraints of the researcher. Such constraints account for the limited number of informant families interviewed and the limited number of interview sessions with each. Further, since informant families were contacted through a single Oncology Clinic, they may in fact represent a
specialized sub-group of the theoretical population of families living with cancer.

Summary

In this chapter, the problem and purpose of the study have been introduced, and the methodology has been briefly described. The literature from which a conceptual background for this study was drawn is reviewed in Chapter 2. Chapter 3 describes the process by which the methodology was implemented in this study. The accounts given by families in the study are described and explained in Chapter 4. Chapter 5 constitutes a discussion of the accounts in terms of the literature presented in Chapter 2 and other relevant literature. Chapter 6 summarizes the study and states the implications of the findings.
Chapter 2

Review of the Literature

Introduction

This chapter will present a review of bodies of literature which are intimately linked to the stated purpose of this study, to describe and explain the family cancer experience from a family perspective. In order to add a family perspective to what is already known and understood about the cancer experience, it is essential to establish what that common knowledge and understanding entails. The literature review will therefore address not only the knowledge available, but also the methods by which it has been acquired.

The literature to be reviewed is that which pertains specifically to the experience of the family of the adult with cancer, subsequent to diagnosis and prior to the advanced or terminal phase of that illness. A discussion of the current status of family study in relation to the cancer experience will be presented. Research that has addressed some aspect of the family cancer experience will be reviewed. Discussion of the limitations of that research base will lead into a description of some of the theoretical approaches to the family cancer experience that appear in the literature. Since much of what is commonly accepted as relevant to the family cancer experience is not research based, this discussion will locate the present study within the context of general theoretical perspectives. Discussion of this theory base will be limited to the psychosocial aspects of the experience (as opposed to medical, financial, religious, etc.) and will utilize as its organizing framework four broad themes, which themselves have emerged from the ideas in the literature. These are (a) Family emotional state, (b) Family roles, (c) Family
communication, and (d) Family philosophy.

Thus the literature review will locate the purpose and method of this study within the general evolution of family theory. It will also describe the common understanding of what the family cancer experience entails as reflected in the research and theoretical literature. This literature review, then, provides a basis upon which to guide the research process toward answering the research questions. In Chapter 5, the findings of this study will be examined and discussed in relation to this same body of literature. In addition, further related literature will be drawn into that chapter as necessary to explore and discuss the descriptions and explanations generated by the families, and presented in Chapter 4.

Studying the Family

Nurses, other health care professionals, and lay persons have, in recent years, published an abundance of literature demanding a holistic, family-oriented approach to cancer care. In spite of this demand, the body of available knowledge about the experiences of families with cancer is underdeveloped. Little is known about the ways in which families deal with cancer, or the factors that differentiate between families who cope effectively and those who do not (Litman, 1974). Miller et al. (1976) believe that this poverty of knowledge about families with cancer allows them to be deprived of systematic care. Hartman (1980) further claims that our lack of understanding serves to reinforce the feelings of these families that they are isolated from the rest of the world. While opinions about what these families contend with abound in the literature, few of the theories are grounded in research.
It is important to note that the study of families in relation to any illness is a relatively recent occurrence. Although events in the family have long been of interest to health care and other researchers, attempts to conceptualize these events using the family as a focal unit for study have rarely been undertaken (Handel, 1974). "Our knowledge of the family is like a giant picture puzzle in which some pieces are missing, other pieces do not fit together well, and only a few sections provide clear images" (Glasser & Glasser, 1970). R.D. Laing (1969) blames the absence of essential family research on the complexity of the subject: "we have taught ourselves that it is useless to ask questions, when we have no methodology to answer them."

Despite such hurdles, some family-oriented health care research has occurred. Often such study of families is facilitated by adherence to one conceptual definition of family. The family as an entity having 'needs', for example, serves as a guiding perspective for Molter (1979) and Breau and Dracup (1978) in their quests for information about relatives of critically ill patients. Definition of family function as 'coping' or 'adaptation' provides a conceptual framework that justifies the search by other authors for behaviors or stages within those processes (e.g., Brodland & Andreasen, 1977; Geary, 1979).

Although conceptualizing the family in such a fashion provides research direction, it is not altogether consistent with the trend away from viewing the family as an entity concerned about the ill member, and toward a perception of family as the basic unit in which illness is experienced (Litman, 1974). Conceptualizing the family as a whole precludes over-reliance upon research direction taken from views of family that represent selected parts of that whole. More holistic models, such as systems theory, promote a basis for understanding how cancer in a
family member dramatically alters the cognitive, social, and emotional patterns of that family system (Wellisch et al., 1978).

While this latter view of family supports the urgency of studying the family unit as a whole, it does not in itself provide an immediately obvious direction as to how this may be accomplished. For this reason, this study will not be guided by any one theoretical approach to conceptualizing the family but conceptual categories will be constructed from the family data itself.

Studying the Family Cancer Experience

Since the family unit as a target for study presents methodological and conceptual difficulties for researchers, much of the relevant research knowledge available to us is based upon the study of individuals as cancer patients or as family members.

The two areas in which the family's cancer-related experience has been examined in some depth are the specific situations of the family with a member dying of cancer (Bahnson, 1975; Leininger, 1977) and the family with a child with cancer (Brody, 1977; Welch, 1981). A common approach to the examination of these selected experiences is the identification of parallel stages through which individuals and families are presumed to progress. Theorists have identified specific "psychological tasks" that families must accomplish in order to adapt to or resolve the crisis (Goldberg, 1977; Kaplan, Smith, Grobstein & Fischman, 1977; Kubler-Ross, 1974). The families of both children with cancer and adults dying of cancer have been identified by these theorists as high-risk groups for psychiatric and physical illness, and for interpersonal relationship disturbance (Bahnson, 1975; Brody, 1977; Kaplan et al., 1977). Since it has not been established that there is any direct relationship between the
experience of families in these situations and that of families living with cancer in an adult member, further review of these bodies of literature will not be included in this chapter.

Where family members of adult cancer patients are addressed in the literature, they are commonly conceptualized as experiencing a 'life crisis'. The crisis concept as applied to illness provides direction for inquiry into such components as stages, coping tasks and strategies, and premorbid patterns (Moos & Tsu, 1977). Much of the research to date is, therefore, descriptive in nature and addresses itself toward identification and naming of such theoretical sub-constructs as stages, needs, or strategies. Since it has not been established that crisis is an appropriate model for conceptualizing the cancer experience, such research approaches seem somewhat premature.

Research Findings

The following is a summary of studies found in the literature that relate specifically to the experience of families with a member with cancer. Those studies directed specifically toward cancer in the child or toward terminal care have been excluded for the reasons cited previously.

In an ethnographic study of a 23-bed cancer ward, Germain (1979) included some discussion about the impact of the experience upon families in that setting. She concluded that a major coping difficulty for both patients and families was associated with emotional problems related to loss of independence.

Wegmann and Ogrinc (1981) used a single-case descriptive study to illustrate the value of identifying family grief/crisis response stages in order to plan nursing care that complies with family defence mechanisms. Green (1980) utilized three case studies to demonstrate common elements in
family disruption and relationship to the health care system during the crisis of cancer. She voiced the need for a specific nursing role in relation to family crisis, communication, and co-ordination. In her preliminary report of a larger study to explore family reactions to cancer diagnosis and treatment, Green (1982) commented that "the powerful need of families to relay a great deal of unsolicited information was not anticipated" (p. 56). She suggested that further study of cancer families, guided by a phenomenological perspective, was indicated.

Miller and Nygren (1978) presented a descriptive study of ten family-member/subjects aimed at evaluating an educational program geared to facilitate family adjustment to living with cancer. Their work focussed upon coping behaviors reported by members before and after educational programs. They grouped coping behaviors into five categories: 1. share concerns; 2. displacement/diversion; 3. confrontation/negotiation; 4. projection/ externalization; and 5. rationalization/reinterpretation.

Cassileth, Heiberger, March, and Sutton-Smith (1982) measured anxiety scores of patients and relatives before and after viewing an informational program about cancer. Their unexpected finding was that patients' anxiety scores were significantly lower than were those of their family members. They concluded that this study confirmed the belief that cancer profoundly affects family members.

In a survey of 20 urologic cancer patients and their wives, Curtiss (1981) reported a greater number of anxiety-related behaviors in wives than in patients themselves. Sex-role differences, however, could have confounded that finding. Additional findings reported by Curtiss included heightened awareness of living each day by both partners, little open communication between spouses, and few lasting role shifts within the families.
Leiber, Plumb, Gerstenzang, and Holland (1976) surveyed 38 cancer patients undergoing chemotherapy and their spouses for the purpose of investigating the impact of cancer upon the affectional behaviors of the partners since the onset of illness. They reported increased desire for physical closeness and decreased desire for sexual intercourse in both patients and spouses.

Vachon, Freedman, Formo, Rogers, Lyall and Freeman (1977) reported findings based on a study of women widowed due to cancer compared with widows from other illnesses or circumstances. They found that subjects whose husbands had died of cancer reported different bereavement experiences than did others. An unsolicited theme that emerged from their interview data was the spontaneous reporting by several subjects that the stress of living with cancer was far worse than the stress of bereavement and widowhood.

MacVicar (1975) searched for factors associated with family adjustment following the onset of a malignant neoplastic disease. She measured the impact of cancer in terms of such factors as social participation, family financial status, and health status of family members. Her conclusion was that both the nature of the pathology and the resources utilized by families were of importance in shaping that impact. In a second study (1981), MacVicar described common features found in a sample of 100 families of married male cancer patients with dependent children in the home. She found that role conflicts were a feature of the experience, especially in traditionally structured families. She also reported what she described as a "hopelessness-helplessness syndrome," which characterized a majority of the families in her study. She concluded that the pre-illness status of the family, along with selected demographic factors, was at least as influential as the pathology in
determining family coping.

Welch (1981) surveyed 41 members of adult cancer patients' families in order to assess coping strategies and family needs. Repeatedly reported coping mechanisms included empathizing with the patient, desiring explanations from doctors, and identifying the value of communicating by touching. The need most commonly reported was for nurses to give excellent, personalized care to the patient. The results of this study reflect the focus of research interest in identifying family concerns as part of the total nursing plan for a hospitalized cancer patient. The conclusion that family coping depends upon excellent patient care is one that this writer questions, since the methodology did not take into consideration the possibility that family members might feel socially obligated to list concern for the patient above all else, particularly when being questioned by a nurse within a health care setting context.

These studies illustrate the limitations in the current research-based knowledge. Most studies examine family members as individuals, rather than families as groups of people. They rely heavily on the assumption that crisis theory is a relevant organizing framework for conceptualizing the research findings. Research questions are focussed upon concern about the ill member and the hospital/nursing care experience. Everyday living is largely ignored as a family issue.

This writer, therefore, feels that research-based knowledge to date provides a markedly inadequate portrait of the experience of families living with cancer. It fails to provide a substantial base upon which hypotheses could be formulated. The research does, however, support the contention that cancer is experienced within a family context and validate the argument that families of cancer patients deserve attention in health care research.
Theoretical Perspectives

There exists a vast body of theoretical literature that relates directly to the family cancer experience. Social scientists, health care professionals, and lay individuals with personal experience have generated an abundance of books and articles that address or allude to the issues in question. Much of this literature reflects individual opinion or assumes a common understanding of the nature of the cancer experience for families. Little of the material is grounded in research. Where theorists do refer to research findings, such references tend to be limited to applications and generalizations of the research of other phenomena rather than specific studies of the family cancer experience.

Although a consistent portrait of the experience could not be inferred from the body of literature, it was possible to extract general themes that appeared relevant to the family cancer experience. A sampling of the literature from which the themes were drawn will be presented in the following pages. Since these themes form the conceptual base from which this study took its direction, the following discussion demonstrates the rationale for the foci selected for the study.

Family emotional state

A number of authors describe what they believe families cope with when an adult member has cancer and offer theoretical explanations for their observations. Cantor (1978) describes the social "image" of cancer as a factor responsible for much of the anxiety experience by family members. Van Scoy-Mosher (1978) believes that assessment of this "cancer set," or set of preconceived notions, is an essential element in the planning of cancer nursing care.

The emotional state of families with a member with cancer is
characterized as "perpetual psychological limbo" by Wellisch et al. (1978, p. 228). Hartman (1980) describes the feeling as "constant uncertainty, an awesome mingling of hope and despair, courage and fear, humor and anger" (p. viii). Van Scoy-Mosher adds the sense of loss of control to the picture.

Although such responses by the family can be explained in part by their concern for the well being of the patient, the day-to-day context of living does not cease because one member has cancer. "Moreover, serious illness does not simplify life by eclipsing other problems; it adds one more large one to those that are already there" (McKhan, 1981, p. 41). While cancer in the family produces emotional disruption in individual members, it also results in family system disequilibrium. Johnson and Norby (1981) describe three ways in which this can happen:

Cancer (1) can threaten or disrupt extant patterns of interaction within the family unit itself; (2) can upset the family's objective future plans and orientation; and (3) may alter the constellation of external reference groups with which the family interacts. (p. 23).

Van Scoy-Mosher argues that no matter what the phase of illness or mode of treatment along the continuum from diagnosis to terminal illness, the family constantly strives to bring back "some degree of equilibrium into their existence" (1978, p. 22).

Although theorists frequently suggest that families differ in their capacity to deal with this burden of living with cancer, they offer little in the way of concrete predictors of families at higher risk. The most consistently proposed predictor is the history of past crisis coping by the family. Speese-Owens (1981) notes that relevant history in the assessment includes past crises, current crisis plans, and the realization of the need for outside help. Wellisch et al. suggest that "inability to
adjust emotionally to cancer is not a unitary phenomenon but the latest example of long-term difficulties in the family system, especially in adjusting to life changes" (1978, p. 228). Thus whether the cancer experience directly causes the disruption, or is a situation in which latent disruptions become overt, the authors seem to agree that disruption in family emotional state is a significant aspect of the experience. They variously attribute this to factors inherent in the family, the society, or the disease itself. They describe the constellation of observable phenomena in terms of crisis, system disequilibrium, or psychological reaction to the presence of cancer. Although each viewpoint holds a degree of common-sense merit, its utility in explaining the meaning that families place upon their own experience has not yet been established.

**Family roles**

Family roles, along with family communication and family philosophy, emerge from the literature base as an arena in which families seek to correct or minimize the disrupted state in which they find themselves when one among them is living with cancer. Role shifts can become "primary obstacles to the successful management of stress" (Cantor, 1978, p.145). Since roles provide a means by which many families maintain stability and comfort during crisis, attempts to reorganize them can compound the disruption of the cancer experience and evoke considerable anxiety.

Role changes, in turn, radically alter the family's capacity to retain a semblance of normalcy in everyday life. The weight of new responsibilities "can become insurmountable, destroying normal family associations, devouring time needed for rest and recreation, and depriving family members of wholesome opportunities for expressing anxiety and resentment" (Hartman, 1980, p. 16). Thus the experience may not only add
new stressors to families but may also render them incapable of carrying on with their normal living behaviors (McKhann, 1981). These theoretical perspectives suggest that the manner in which families allocate and perform role functions may have a significant impact upon the way in which cancer affects their everyday life.

**Family communication**

Communication within the family unit may be disrupted dramatically by the emotional turmoil of the individual members. When the experience of living with cancer is viewed in terms of adaptive task progression, and each individual progresses at his or her unique pace, families may face the additional difficulty of adjusting to individual reactions that are out of phase with the rest (McKhann, 1981). Individual needs for emotional support may fluctuate radically, and members (including the patient) may be forced to take on the role of emotional arbitrator for each other (Speese-Owens, 1981). Hartman (1980) theorizes that families who share feelings with each other experience less difficulty dealing with the cancer experience than do those in which members characteristically solve problems alone. Thus communication within the family is perceived as a significant factor influencing the family's emotional status.

A review of the lay literature, however, suggests that the functions of communication about the cancer experience may extend beyond immediate emotional support. One is struck by the disproportionate number of individuals who have elected to relate the tale of their family's cancer experience by writing a book about it (e.g., Bayh & Kotz, 1979; Brownstein, 1980; Cook, 1981; Fox, 1979; Humphrey, 1978; Ipswitch, 1979; Kaehele, 1952; Lee, 1977; Loewenstein, 1970; Lorde, 1980; Rollin, 1976; Sarton, 1980; Sveinson, 1974). The predominance of these personal
accounts in the lay literature may support the belief held by several theorists that an urgent need of the individual undergoing a cancer experience in his/her self or family is to communicate the experience to others and to be heard (Linn, Linn & Harris, 1982; MacDonald, 1979; Schnaper, 1977). Thus, although there is agreement that communication is a major factor in the way families experience the cancer, the meaning or potential meaning of their communications has not been established.

**Family philosophy**

As has been suggested earlier in this review, the presence of cancer may disrupt a family's objective future orientation and planning (Johnson & Norby, 1981). The uncertainty about the future that occurs with a life-threatening illness has been articulated as a major negative force upon the emotional state of the family (Hartman, 1980). It seems a logical extension to suspect that cancer might have a negative impact upon a family's outlook on life or attitude about the future.

Curiously, though, there are a number of authors who focus instead upon positive philosophical changes that are said to occur in individuals and families as a result of having experienced cancer (Ehike, 1978; Kelly, 1978; MacDonald, 1979; Rosenbaum, 1975). Although the detailed description of these growth experiences may be found in the lay personal accounts, their prevalence has also been noted and articulated by health care professionals. Thus it seems appropriate to expect that attitude or life philosophy changes may be a feature of the way a family experiences cancer, although the nature and direction of such change is not yet adequately understood.
Summary

The lay and scholarly literature offers abundant opinion as to the nature of the family experience when an adult member has cancer. Without research-based criteria, however, it is impossible to extract from that body of material a coherent or consistent portrait of the experience. This writer, therefore, concurs with authors who have lamented the dearth of research in the area of family experience when an adult member has cancer. While we have a vast body of theoretical material that urges nurses and other health care professionals to care for families rather than just cancer patients, we lack guidelines as to how to plan or administer this care. This writer believes that if nurses fail to understand the meaning of the experience to families, they have no sound basis upon which to predict problems, provide support, or assist in the prevention of future difficulties. While the theories available to us offer some common sense validity, one cannot ethically assume that they are universally relevant.

This study has been designed to explore the perspectives of families who themselves are living with cancer and to utilize those perspectives to generate description and explanation of the phenomenon. The phenomenological paradigm of qualitative research, as introduced in Chapter 1, has been selected as the most suitable methodology to guide this exploration. The manner in which the method was applied to the research questions in this study will be described in the following chapter.
Introduction

The phenomenological paradigm of qualitative research theory and methodology served as a guide for the methodological approach to this study. The following chapter describes the manner in which the method was interpreted and implemented in the selection of participants and in the collection and analysis of data.

Selection of Participants

The principle of theoretical sampling directs the researcher to acquire informants during the course of the research for the purpose of answering specific questions. The competency of participants is determined by their ability to provide the knowledge and understanding that is sought. This ability is related to such factors as the informants' participation in the experience for sufficient time to become "enculturated," and their ability to communicate their experience without undue analysis, interpretation, or objectivity (Spradley, 1979).

Criteria for selection

The criteria used in selecting families for participation in this study included the following:

1) an adult member who is currently under treatment for some form of cancer;
2) awareness by both patient and family of a cancer diagnosis;
3) a minimum of two months elapsed time since that diagnosis;
4) a judgement by the referring physician that the individual is not
presently in the terminal stages of illness;

5) geographical proximity to the Greater Vancouver area; and

6) the ability to communicate in English.

Since the first several families to participate in the study were those with an adult member whose age was approximately 60-years old, age range was included as a selection criteria for the later families included in the study. It was the opinion of several of the families that their experience with cancer might well have been different had it occurred, for example, when they were a young, child-rearing family. In deciding to narrow the focus of the study to families in mid-older adulthood, the researcher hoped to gain a richer portrait of this sub-group at the expense of a broader range of experiences. Thus an additional selection criteria was as follows:

7) a cancer-patient member whose age ranged from 55 to 70 years.

Selection procedure

Families were selected from one Oncology Out-Patient Clinic in the Greater Vancouver area. The list of clients attending the clinic in any given week was reviewed by members of the Oncology team (physician, nurse clinician, social worker, and pharmacist) in consultation with the researcher to establish the compatibility of clients with the research criteria. Beyond these criteria, the team tended to veto families in which hospitalizations or vacations might make them unavailable for the study.

When a family had been identified as a suitable candidate for participation in the study, initial contact was made by the physician or the nurse clinician during the clinic appointment. The Information and Consent Form (see Appendix A) was given to the patient, along with a brief
explanation of the relationship of the researcher to the clinic. Upon reading this form, if the patient indicated willingness to meet the researcher, the introduction was made at that time. Patients were encouraged to take the form home and discuss it with their families, and appointments were made for telephone contact by the researcher. During this subsequent telephone contact, families who agreed to participate made appointments for the home interview.

Departures from this procedure occurred in a few instances. One family approached the interviewer in the clinic to request that it be considered for participation. In other instances, the family group was present at the clinic and consented immediately to participation, arranging the home interview at that time. Some families signed the consent form and returned it to the researcher while still at the clinic. In these cases, a second copy was given to them to re-read at home. Most families, however, signed the consent form at the beginning of the initial home interview. Although written consent was only required of the cancer patient, it was always obtained in the presence of the other family members.

Three of the families who were approached declined to participate in the study. In the first case, the patient anticipated that the stress of an interview might be detrimental to his partner's health. In the second case, consent was given, but a series of appointments for home interviews was broken by the family due to unanticipated events in the patient's course of illness, resulting in his death a few weeks later. The third family expressed an eagerness to be involved in the study but a reluctance to commit themselves to an appointment. After several telephone conversations, they explained to the researcher that planning anything ahead of time was contrary to their style of coping with the changes
brought about by cancer.

Characteristics of the participants

A total of eight families participated in the study. Four families consisted of male patients and their wives. Two consisted of female patients and their husbands. In the remaining two families, the patient was a widow, and the family members were female relatives. In one family, a grown child participated in one of the interviews. The number of informants, therefore, was seventeen members of eight families.

All participants were English-speaking Canadians who resided in or near Vancouver. Most of the family groups had been together more than twenty years, although two of the non-spouse family members did not currently reside with the cancer patient. Two of the cancer patients and three of the family members were employed. The remainder were unemployed, had retired, or were on leave from work due to health reasons. The socio-economic situations of the families were heterogeneous, and the style of living varied markedly within the sample. The ages of the individuals with cancer ranged from 59 to 66 years at the time of the study. All of the spouse family members were from approximately that same age bracket, while one non-spouse family member was older, and two were younger.

Of the eight individuals with cancer two had breast cancer, and two had lung cancer. The remaining four had stomach cancer, bowel cancer, Hodgkin's disease, and multiple myeloma. In relation to these cancers, five had completed at least one course of chemotherapy, while the other three were receiving chemotherapy at the time of their participation in the study. Five individuals had undergone one or more surgical procedures in relation to their cancer, and two had received radiation therapy. All patients had been treated by the same physician in the Oncology Clinic,
although most had many other physicians involved with their treatment at various phases of the experience. At the time of their participation in the study, the families had been living with the fact of a diagnosed cancer for periods of time ranging from three months to five years, the average being about two years.

Data Collection

Although the processes will be presented separately in this discussion, data collection and analysis did not constitute distinct phases of the implementation of this methodology. Data were analyzed throughout the entire collection phase, and, in turn, analytic material influenced the data collection process.

The data were collected in a series of intensive interview sessions in the homes of the participant families. A set of sample questions was constructed for the purpose of providing a loose structure for the initial interviews (see Appendix B). The questions included in this list evolved from the problem statement for this study and took into consideration the themes extracted from the review of pertinent literature (Chapter 2). No attempt was made to standardize the interview process between families; rather, the guide simply served as a tool for facilitating exploration of the general content areas when they did not emerge in the family's accounts spontaneously. As the data collection phase progressed, areas of concern were added to or deleted from this original list. Such changes reflected the themes that emerged as significant from the perspectives of the informant families and facilitated an increasing depth of exploration within those themes.

The data were constructed through a series of eleven interviews with a total of eight families. Following an initial interview with each of
six families, a period of systematic reflection resulted in a more specific focus to the investigation. When three of these original families were unavailable for a second interview (one patient had been hospitalized and subsequently died; one family left the country in search of alternate treatment; and one family declined to be interviewed again due to a busy schedule), an additional two families were recruited. In spite of the fact that these families had not participated in the initial round of interviewing, and thus had not contributed to the data that shaped the second interview approach, the depth and richness of their accounts were comparable to those with which rapport had been previously established. The acquisition of these new families at this point in the process ultimately proved fortuitous in that their validation of the themes and relationships extracted from the original informant group enhanced the researcher's confidence both in her interpretations and in the credibility of her data.

The interviews themselves took place over a period of 2 1/2 months. They ranged from 1 1/2 to 3 1/2 hours in length and totalled 26 1/2 contact hours. Of that, a total of 13 hours of dialogue was recorded on audio tape, 45 to 90 minutes per interview.

Although families seemed to speak freely in the presence of the audio tape recorder, several of them requested that the machine not be restarted once the first cassette tape was completed. Many used the occasion of the automatic shut-off to serve refreshments or to talk about topics unrelated to their cancer experience. When significant subjects did enter into the ensuing conversation, their substance was recorded in field notes made immediately upon leaving the interview.

While all families were extended the option of stoppage or erasure of the tape at any point, only one elected to do so. In this case, a portion
of tape that included mention by a family member of financial status was erased in the presence of the family. In the same interview, the tape was also replayed in part to the family, since one member had never heard the sound of his recorded voice and wished to do so. The lack of inhibition in the presence of the tape recorder of this and other families was reflected in the permission given by several for the researcher to play the tape to other patients or families. Although the confidentiality guaranteed to the participants precluded such use, the researcher thanked them for the offer and restated the general contribution they had made by participating.

The verbatim transcriptions of audio tapes and the detailed field notes made after each interview formed the bulk of the data base for this study. Field notes were also made following all telephone conversations in the course of planning and arranging interviews. Included in these notes were summaries of the conversations with members of the three families who declined to participate, since several of these conversations lasted over 30 minutes and included much unsolicited discussion of the themes within the research. An additional data source evolved from the request made by two families that the researcher attempt to include their grown children living away from home in the study. In response to this request, a standardized letter (see Appendix C) was sent to each of seven children from these two families, inviting them to make written contributions if they wished. Two lengthy and detailed responses were received.

Rapport between the researcher and the participant families was established with no major difficulties. Many expressed pleasure at being asked to make a contribution to nursing knowledge in general and to the researcher's learning in particular. Families tended to place the home
interview in a semi-social context, in that refreshments were always served, and most families requested that the researcher remain longer and "visit" after the "interview" was completed. Families seemed eager to be believed by the researcher.

*FF: Now are we...am I uh...?
R: Yeah. You're telling me very interesting things.
FF: Uh...uh... some people don't want to listen to my stories because they're not true. But they are true.

Their efforts to validate their stories often extended to providing tours of the home, looking through photograph albums, and bringing other artifacts and memorabilia out of the closets to show the researcher. It was the researcher's impression that the participants enjoyed the experience of being listened to:

MC: You being a nurse...I mean...you see all these kinds of things and you know, it...you understand it.
R: Well I've certainly appreciated hearing what you had to say.
FF: I was interested in you too because I...I mean I've never had an interview like this before...and uh...it's nice to talk to someone who knows something about it.

Construction of accounts

The construction of accounts reflected an evolving interaction between the participants and the researcher. The researcher approached the study with a set of initial questions that reflected prior assumptions and understandings. Throughout the course of data collection, these assumptions were revised, affirmed, or discarded as the expert witnesses described and explained their realities. A greater degree of common

*Note: R = researcher
FC = female individual with cancer
MC = male individual with cancer
FF = female family member
MF = male family member
understanding between the researcher and participants evolved over time, facilitated by the use of validation, reflection, and restatement throughout the interviews. As the researcher's understandings of the experience shared by the participants grew, the increased richness and depth of the data that emerged from the interviews appeared to reflect that growth.

The accounts not only describe but also explain the phenomenon as perceived by the participants. Although families required little prompting to talk of their experience in detail, it was only as the researcher's facility with asking the "right" questions developed that the explanations also began to emerge. The researcher's impression was that this explanatory layer of the account was a product of the "right" questions rather than the degree of intimacy in the research relationship. This impression was supported by the richness and depth of the explanations offered by the two new families who participated only at the later stages of the study.

**Ethical considerations**

Prior approval for this study was obtained from the University of British Columbia's Screening Committee for Research Involving Human Subjects. The rights of participants were protected in the following ways:

1) No interviews occurred without the written consent of the patient on behalf of his or her family.

2) A description of the study and an explanation of the researcher's expectations of participants was made available to patients and families prior to obtaining consent (see Appendix A).

3) Both patients and families were advised that non-participation in the study would in no way affect the treatment or care they received.
4) Prior to interviews, all family members were reminded that their right not to participate, by leaving the interview or by remaining silent, would be unconditionally respected.

5) Patients and families were informed that taped material would be kept anonymous and confidential, that tapes would be erased upon completion of the study, and that written material and transcripts in relation to the study would not use any names or identifying factors.

6) Participants were informed that participation involved no expected risks. Potential benefits to the families were limited to those inherent in contributing to nursing knowledge and to the process of communicating experiences as a family.

Data Analysis

Throughout the data collection process, the verbatim transcriptions and field notes made by the researcher were reviewed and compared for emergent themes within the accounts. As interrelationships were identified and pieces of data were clustered, the conceptual categories that were generated achieved higher levels of abstraction. Repeated review of the concrete data and validation in ensuing interviews created a means of ensuring that abstractions remained solidly grounded in the data themselves.

Following initial interviews with six families, a tentative analytic framework was developed. It was this framework that guided the scope and level of exploration in the second round of interviews, including those that occurred with the two new participant families. The data that emerged in the second round of interviews shaped the final analytic framework for organizing the data in a manner that would best represent the common experience of the families and enhance understanding of their accounts.
Summary

The methodology for this study was based on the phenomenological paradigm of qualitative research. Participants were selected by virtue of their competence to testify as to the experience of families wherein an adult member is living with cancer. Eight cancer patients and nine family members, to a total of 17 people, participated in eleven interviews over a 2 1/2 month period.

The data were comprised of transcribed audio tapes and field notes from these interviews. Concurrently with and subsequent to these interviews, data analysis took place. The analytic process had an impact upon the data collection, particularly in the latter phases, by guiding the focus of exploration and the depth of meaning sought by the researcher. In this manner, the participants and the researcher together constructed the accounts that will be presented in Chapter 4.
Chapter 4
The Families' Accounts

Introduction

This chapter will present the accounts given by the participant families as they describe and explain the experience of everyday life when an adult family member has cancer. It is recognized that each family offers a unique perspective and experiences the cancer according to its unique circumstances. While no two families tell the same story, certain themes occur repeatedly in the family accounts. The similarities and differences between families within these themes describe and explain aspects of the common experience. The description and explanation that follow use these themes as an organizing framework for presenting the families' accounts. Since the themes are not representative of separate and distinct facets of the experience, the relationship and interactions between themes will become apparent in the presentation of accounts; and it is the intention of the writer that exploration of each of the segments will facilitate an understanding of the whole.

During the interview process, the families constructed accounts that described the impact of cancer upon their everyday lives. Their descriptions differentiated those aspects of life that had changed as a result of cancer from those in which former patterns had endured. The accounts further revealed the criteria by which families measured and evaluated such changes. This descriptive layer of the accounts demonstrated the complex and multifaceted nature of family reality. Juxtaposing and contradictory accounts emerged in this descriptive
process. Apparent contradictions were both alluded to and expressed openly at various times in the process of constructing the accounts. Although some aspects of the cancer experience appear incongruous according to these accounts, it will be shown that they are not perceived as incongruous by the cancer families. While families present descriptions of their experience that include contrasting values and beliefs, they are also able to explain these contrasts and make sense of the apparent contradictions. It is essential that all realities described by these families be assumed to be equally valid, whether or not they appear contradictory. It must also be remembered that the accounts presented here are these articulated by family groups, and thus may include more complexities and contradictions than would those constructed by individual family members. The family cancer experience will not, therefore, be described as a simple phenomenon, but rather as a kaleidoscope of realities, none of which can be fully appreciated apart from the gestalt of the whole.

The descriptive layer of the accounts will form the first section of this chapter. The subsequent two sections will address the two explanatory layers which emerged in the process of constructing the accounts. Thus the three sections of this chapter may be viewed as representing three different orders of account, with the explanatory layers increasing in depth as the chapter progresses.

The second section of this chapter articulates the relationships families identified between their illness experiences and the manner in which they were living their everyday lives. These relationships were expressed in terms of strategic choices made by families as they coped
with the cancer experience. Families explained themselves and their behaviors within the cancer experience in terms of a structure of coping strategies. This second section will address the patterns that emerged within the accounts of those strategic choices. Throughout this section, the concept of attitude will emerge repeatedly in the family accounts. As the explanations of the cancer experience progress through a range of themes in the families' strategic patterns, the association between attitudinal and behavioral strategies will become apparent.

A more thorough examination of attitudes will occur in the third section of this chapter. Attitudes will be presented as the third layer of the families' accounts of the cancer experience. This final layer will demonstrate the families' integration of the multifaceted and contradictory cancer experience into a unified whole. Through the use of attitudes that conform to their unique and characteristic beliefs and values, families explained the manner in which they made sense of and integrated the cancer experience into the context of their lives. Thus this layer of the accounts explains the apparent contradictions that emerged in the description of the impact of cancer and provides a framework with which to make sense of the many realities that coexist in the family cancer experience.

Describing the Impact

This first section of the accounts describes the psychosocial impact of cancer upon aspects of everyday life as articulated by the families. This descriptive layer of the accounts has been organized according to the four general themes that emerged from the theoretical literature review
in Chapter 2 as being particularly relevant to the family cancer experience. Discussion of these themes will be preceded by a brief description of the general impact of cancer as articulated by the families. The contrasts between this general perception and other aspects of the descriptive accounts will become apparent as family emotional state, roles, communication, and philosophy are explored in relation to the impact of cancer. Latter sections of this chapter will explain the presence of contradictory realities within the accounts. It is the purpose of this section, however, merely to narrate those realities in the language of the families themselves.

**General perceptions**

The family perception that cancer had not substantially changed anything was expressed by all the participants. Two families, when approached to participate in the study, indicated willingness to help the researcher, but expressed the concern that they might not be of much assistance since cancer had not really changed their lives. The remaining families articulated this perception as introductory statements in their interviews.

MF: As far as it affecting our lives, we're no different than what we were when we were first married. It hasn't affected us at all. We still feel the same, okay?

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MF: And this...it's...it's just an accepted thing. It's just...we live a normal life.

FC: Nothing's changed so far anyway.
All of the families had experienced chemotherapy as part of the medical treatment for the individual with cancer. When families qualified their perceptions that nothing had changed, several attributed change to specific side effects of that chemotherapy, such as hair loss, lethargy, and nausea.

FF: But it...uh...just seems to be...uh...oh we go on just as usual. We don't...I don't think we've changed anything since. Have we? I don't think we have...

FC: No.

FF: ...changed our way of life.

FC: Except that the only change I have is...uh...two different styled wigs (chuckle).

R: So there's a change in hairdo. That's the only change in your life?

FC: That's the only change I think.

When side effects were described, they were frequently mentioned in the context of what hadn't changed as opposed to what had.

MC: It just takes a lot...as I say...this chemotherapy. The only thing...I'm very fortunate...is all it does is make me tired. I haven't been sick. I haven't lost my hair, thank goodness.

FF: You didn't have any to lose.

MC: Thank goodness for that.

In addition to the common experience of chemotherapy, the families also shared a common maturational stage, at least in terms of the age of the member who had cancer. The perception of aging seemed to be a feature of the general notion that cancer had not produced major change.

FC: Happening now at this stage in my life...um...I don't know that I've slowed down any more...um...than I would have anyway.

..........................
FF: I don't know that there's anything's really changed. It's just that...

MC: Slowed down.

FF: It's slowed down a lot. We don't do something that we might have done before, but then we're getting older too.

Thus where change had occurred, families often attributed it to stage of life or to side effects from chemotherapy. The unanimous assertion that cancer had produced little change was an intriguing introduction to the experience of these families. As the construction of accounts was pursued, however, many changes directly resulting from the cancer experience did in fact emerge and were explained. It is only through an understanding of the experience as perceived and articulated by the families themselves that one can make sense of this initial generalization.

Description of the impact of cancer upon the psychosocial aspects of everyday family life will now be presented in relation to the families' emotional state, roles, communication, and philosophy. Within each of these general themes, the concepts and issues of concern will be identified and described as articulated by the families.

Impact on emotional state

Although the diagnosis experience was not an intended focus of the research interview, diagnosis stories emerged spontaneously as integral memories in the shaping of the families' experiences with cancer. Whether the event had occurred five months or five years previously, the factual detail and emotional overtones of the cancer diagnosis seemed fresh in the
minds of the participants. For many families, the diagnosis story served as a beginning point from which to launch a description of their present experience. The following excerpt from a letter to the researcher demonstrates the drama of that event.

MF: The circus continued. Finally after mom had undergone weeks and weeks of testing and pain in the hospital, the family collected to give mom support while her doctor and the cancer specialist gave the results of weeks of testing. Cancer!

The period immediately following the diagnosis was described by many families as the most emotionally taxing time of the cancer experience to date.

MC: I'd never been sick. And uh...to all of a sudden...here it is...cancer, you know. It shocked everybody.

R: mm hmm.

MC: So I guess that's probably the only...well not the only time but the...that was one of the biggest.

FF: That was the hardest.

Although families acknowledged that emotional disruption had resulted from the diagnosis, they tended to perceive it, at least in hindsight, as something somewhat less than catastrophic.

FF: At first it was a...a dreadful shock to both of us because uh...as you know [she] has never been sick in her life.

R: mm hmm.

FC: Until this hit. And we couldn't believe it. I couldn't believe it. And then, you adjust to all these things.

R: Did that take a long time...that adjustment?

FF: No, it didn't. Uh...once you've accepted it and you knew what it was going to be.
R: When you were first diagnosed with cancer did you find that...that there was a period of time that was very disruptive for you? Or was that a very upsetting time?

MC: Nothing. Nothing at all. It didn't bother me...it didn't...oh maybe it bothered my wife.

R: mm hmm.

MC: And she cried a bit.

R: mm hmm.

MC: But it didn't bother me any.

Thus while families said that cancer had produced no serious disruption in their emotional state, they all did speak of cancer as having an impact on their moods and feelings. Anger was frequently mentioned as an initial reaction to the events associated with the diagnostic and early treatment phases.

FF: I know how I felt when I first heard about it. I felt anger.

FF: You know when I found out that the uh...the doctor didn't do the right thing....She didn't have any chemotherapy after the mastectomy, which she should have had...and uh...of course the anger flared up again at why the...the doctor, being a doctor, wouldn't have known what to do.

Anger that had begun in the early phase persisted for some of the families. The following statement written by a family member demonstrates anger toward past events being experienced in the present:

MF: As you may have picked out by my wording, I am angry, astonished and disappointed with the total crew of doctors and specialists involved throughout the painful ordeal mom has gone through.

Where a target for such feelings was named, it was often located within the health care system.

MF: We're not feeling so much angry as bitter about it.
R: Bitter?

MF: From the general run-around.

Feelings of uncertainty were also commonly mentioned and were described as a fundamental adversary to the emotional well-being of the cancer families.

FF: I think it's...it's the unknown. Cause every time that [he] goes down...well now we've reached a point that we actually know this tumour is acting up again, and uh...but every time waiting to find out what's the diagnosis...what are the doctors going to say and um...then he comes back and says, "Well they've done another test." And it's just continuous. It's the unknown of all of it. It's the unknown. Not knowing what the next test...or how long you're going to have to wait. And he gets really keyed up on a day we're going to know the results, and then he comes home and, "Well they're going to do a scope," or whatever, you know. I think this is the hardest.

.................................

FF: People fear the unknown more than anything else. I don't blame them.

Emotional reactions to the uncertainty were apparent in all families and were expressed in various fashions.

FF: Oh I am worried, you know.

.................................

FF: It's a real downer.

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FF: I'm a tense type of person. I'm a...you know I'm fairly hyper. Um...I can get very keyed up and emotional over things and I know there are times I can feel it, you know...I can feel that. I have a tendency to suffer from a type of migraine or tension headaches, and this has definitely increased, you know, since this has happened. Um...it's just um...'course I don't think it's as much of a worry...I mean we're looking at it now. I don't know how I'm going to be when um...I suppose the Lord will give me strength when [he] becomes really bedridden.

.................................
FF: I know I find uh...every once in awhile you just sort of...you wake up crying. I don't think at times that I've been dreaming. Maybe it's release of pressure. I don't know. Um...I'll wake up some mornings and uh...just suddenly start crying, and I don't think it's just that it's built up, and you know um...

R: mm hmm.

FF: I guess you have...you have to let it go. You have to.

Irritability associated with the after-effects of chemotherapy was a feature of the emotional state of some of the individuals with cancer.

R (to FF): So it doesn't upset you too much that he's irritable?

MC: Oh no. No, we...we're very compatible the two of us.

R: mm hmm.

MC: Yeah. Like uh...maybe I might get mad at her and then two minutes time just..."Don't you want something to eat, love?" And then that's it. That's all forgotten (laugh).

FF: But that's the way it does affect him.

MC: Yeah.

FF: Irritable. That's about the worst part of it, I guess.

..............................................................

MC: She's worried even now.

FF: Well you do because he gets so tired sometimes and you know...

MC: Says I get cranky (laugh).

FF: Well...

MC: I will be honest (laugh).

R: He gets cranky, eh?

FF: Hmm...well he...
MC: Probably I did you know. Sometimes I probably was irritable a little.

Although it was frequently mentioned by the families, irritability did not appear to be a particularly disturbing aspect of their day-to-day living.

MC: And uh...as I say...My bitching, and I...realize that I have done a lot of moaning and complaining and bitching and shit like that.

FF: When you're not feeling good, you do those things. (pause) And if he's not complaining, there's something wrong (laugh).

R: Is this a change...this complaining? Or is this...

FF: No. He done that all his life.

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FF: No.

FC: Not any more than usual (laugh).

FF: Just the same (laugh).

While emotional reactions were discussed by patients and family members alike, several of the patients expressed the opinion that their partner had suffered the lion's share of the emotional impact of cancer.

MC: She took the brunt of everything.

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MC: I think it's a little tougher on...uh...the partner, 'cause the fact is that...you know...I'm the one that has the pain whenever I have a pain, which very fortunately I haven't had too much yet, and so it's a little harder on the partner than it is on the person who has it I think. At least that's the way I feel. You know I've found um...maybe in other families it's different, but that's what we feel.
Although the partners did not necessarily concur with the viewpoint, the families clearly indicated that the emotional impact upon family members was at least as extensive as the impact upon the patients themselves.

R: You think it'd be better if you had it than if he had it?
MC: (laughs)
FF: Yeah well look at...look at him. uh...uh...suffering so much, you know what I mean.
MC: Oh no. That's not...
FF: It sounds stupid I know.
MC: ...not that bad.
FF: But anyway...
MC: Oh no. Not that bad. I didn't say you were stupid, I said it's not that bad.

Thus, while families described emotional reactions as a component of their experience with cancer, their perceptions during the time at which accounts were constructed were that emotional turmoil was not characteristic of their everyday lives with cancer.

FC: And as I say, we have a pretty good life, don't we?
FF: Yes we do. Very good.

**Impact on roles**

Temporary or permanent role shifts occurred in all of the families. For four of the cancer patients, the family role prior to the onset of cancer had been that of wage earner. At the time of interview, only two had maintained that role, and both of these had been temporary absences from work as part of their cancer experience. The usual family role of the remaining four cancer patients had been that of sole or shared
homemaker. Most of the family members had maintained their prior roles throughout the cancer experience, with the exception of one who terminated employment to become a first-time homemaker, and one who became a wage-earner for the first time. The experiences of role loss, role modification, role gain, and role retention were described by various families.

Where family roles were lost by the member with cancer, physical disabilities related to the cancer accounted for those losses.

MF: I mean there...there are things that...that my wife...er...wife is incapable of doing now that she was able to do before.

..............................................................

FC: Well I can't do what I used to do.

R: mm hmm.

FC: Is that what you mean? I can't accomplish what I used to. Like I've got it in the back and in the uh...hips. So I...automatically there goes the housework.

Several patients perceived such role losses as temporary rather than permanent changes.

FC: Things I would like to have done and haven't done in the past would be to wash the kitchen walls all out there the once a year. They haven't been done for two years. We'll get it done.

R: mm hmm.

FC: We'll slowly do it.

..............................................................

MC: I would like to be doing more volunteer work, but uh...I find that I get...with all the noise and confusion it just makes me tired. So it's...no sense me doing it. I'll get back to it, you know, very shortly. I'll start going back to it.
While not all patients had experienced major role losses, all had been required to make some modifications in their usual role functions as a result of having cancer.

**FF:** So I've been keeping house, and [she's] been working.

**FC:** Right.

**FF:** So...which worked out fine for both of us. And of course uh...uh I've tried to make sure she didn't have to do any bending, or anything that she....

**FC:** Spoiled rotten...uh...in other words (chuckle).

In order to ensure that the tasks associated with their roles were being carried out, some of the patients relied upon external services they previously would not have used.

**MC:** I'm going to have a contractor come in...put the cement in. I used to do...I've done all my own cement work around here. But when you start turning sixty, you start throwing cement around, you know. There's quite a bit.

**FF:** Plus you haven't got the strength anymore.

**MC:** Yeah. And uh...you have to face up to the fact where...it'll cost you say $700 to do it yourself, it's gonna cost you $1500. But you can't do it yourself, or you're not gonna get it done.

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**FC:** He's been great, you know, to...that is a big worry off my mind. I like to have my house nice...and tidy. It was before, and it's been now, you know, and it's a...that's a big worry off.

**R:** So the homemaker....

**FC:** ...to have them coming. Yes.

**R:** That makes a difference to you.

**FC:** Oh yes. That's a great program for...you know, like...men don't notice it. My husband couldn't care less if the rug gets vacuumed or the dusting's done. But I notice it.
Where the families found themselves unable to carry out previous tasks, they were often forced to alter their expectations.

R: Does that worry you, or do you just forget about the yard?

MF: No, I don't bother being upset.

FC: Yeah. I don't like that crap all over the yard (laugh). My sons said they would come and do it...like, you know. But they...they've got lots...they've got a child...two of them...and they've got to look after their house.

R: mm hmm.

FC: So they haven't gotten around to it. So you can't...I asked once, and if...if they can't, they can't. That's all.

Several of the cancer patients described modifications they had made in the way they accomplished their previous roles.

R: Have you had to give up doing things around the house that you used to do, and other things for yourself?

FC: Not really. I can still do my housework.

R: You can.

FC: mm hmm. Only if I get tired then I quit, you know. I don't force myself to do too much. Like if I feel nice today I do a lot and tomorrow I might not feel right. Forget the housework.

R: mm hmm.

FC: That's the way to do it. No use forcing yourself.

While some families expressed such modifications as minor adjustments, others described a process of re-learning associated with the changes in previous capacities.

FC: And you know when you're a...a very independent person...and uh...we were sort of raised in the old school where if you want something done, do it yourself, you know.

R: Yeah.
So, you just sort of automatic go to these things. So I had to uh...sort of re-learn that uh...uh...you know...there's a time and a place for everything now that uh...you just stop and think, "Well no...uh...I better not do that." So you get somebody else to do it, but it's...it's...it's against my whole nature really.

mm hmm.

But uh...you learn. You learn and uh...perhaps you get a bit more self-centred, I don't know.

In one family, the partners had switched roles from the ones they had fulfilled prior to living with cancer. The re-learning associated with the perception of loss of former capacity was expressed with a similar tone of regretful acceptance.

So now I'm home everyday and I'm doing the housework and I'm doing the grocery shopping (chuckle) and....

And I'm travelling up and down the valley (chuckle). We've reversed roles.

We've just reversed roles, so that is definitely...you know. But I...I have no problem accepting it. I don't regret this, but again that's my makeup. I'm calm and uh...to me to sit and read a book or go for a walk in the park or go for a bike ride is great! It only bothers me the fact that while I'm loafing around, this lady's driving all over the country. And that bothers me 'cause I should be doing it, not her. But this is the way the roles had to be reversed and there's nothing we can do about it, so we have to accept it and go along with it. But it does change your life, that's for sure.

Thus, although families did not describe major disruptions resulting from alterations in their usual role allocations, where changes or modifications were perceived as losses from former capacities, they were expressed as unwelcome changes.

Role gains, on the other hand, were described by these families as more positive experiences. None of the husbands who had acquired
homemaking duties as a result of the wife's incapacities from cancer described this as a difficult change.

FC: Well I've learned about my husband more...like uh...what a strong person he really is.

MF: Good cook and bottle washer (laugh).

FC: Oh sure. Not much of a cook (laugh).

FC: Oh yes. My husband's been wonderful. He's...he's just been so helpful, and he never had to keep in the house before...in his life. His mother was active enough and he never had to do anything and now he has to. That's all there is to it.

R: Well how's that changed for you then...having to take on extra jobs that you didn't have before?

MF: Oh...wrecks my leisure time (laugh). Oh no. Don't bother me at all. It's something we got to contend with, so....

Several male cancer patients had also acquired household responsibilities as a result of their illness. These role acquisitions were described as neither unpleasant nor disruptive.

R: Well how have your...have your activities changed or the...who does what around the house? Have these changed a lot since you got cancer?

MC: Well I...I do quite a bit, like she said. I do quite a bit of cooking. It keeps me occupied. It keeps me out of her heels. She does other things. She washes the dishes, I do the cooking.

FF: He does all the grocery shopping and everything because um....

MC: And the house...you know, the housework and so on. I don't mind doing it at all. It's great. And it keeps me busy.

The value of such household role acquisitions was described as that of providing a sense of accomplishment and helping the patients avoid pre-occupation with their illness.
FF: I get you to do things that uh...you know...go out and get things. Like going shopping.

R: mm hmm.

FF: Or he can do the cooking.

MC: Well uh....

FF: You see...'course it's not like I'm lazy. I could do the cooking but then he...it keeps it off his mind.

MC: Occupied. Occupation uh...doing something.

FF: Get something...get something done, you know. Several families also described roles that had been retained in spite of cancer. The maintenance of prior roles was valued by these families.

R: Have you changed who does what around the house and...uh...the way you carry out your normal everyday activities?

MC: No. I still wash the dishes.

FF: (chuckle) And cook.

R: She keeps you busy.

MC: And I cook, yeah.

FF: Sure I keep him busy!

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FF: He's got to do his share of the work.

R: Yeah?

FF: That's right. He's not crippled. Oh no.

R: You're not going to let him slack off, eh?

FF: No way. He's not going to slack off. That's his job every Monday morning...go downstairs and do the wash. And he vacuums. He's a good cook. Oh yeah, he's a real good cook.

Families also seemed to value role retention by their non-cancer-patient members.
R: Were you tempted to give up some of those things that you do when your husband got ill?

FF: No way. No.

MC: I don't want her around here!

Thus, although all of the participant families described roles and role changes as significant within the context of their everyday lives, none claimed to have experienced major disruption with regard to roles. Within the process of re-shuffling, role gains and role retentions were used by many of the families to counteract the discomfort associated with role losses. Where roles could be retained with the use of modification, families described them with a measure of pride. Role losses were experienced as minor inconveniences when the families expected such losses to be of a temporary nature. It seemed apparent from the accounts of these families that perceived role loss was a significantly more difficult aspect of the experience than was any other form of role reorganization.

Impact on communication

The participant families all addressed the issue of whether or not to tell friends and acquaintances that one of their members was living with cancer. Most families had chosen to inform those within their usual social networks.

R: Have you talked to people about your husband's illness?

FF: Oh yes. Oh yes.

R: That's something that you can talk about?

FF: My friends all talk about it. Oh yes. All my friends, they know about it.
All the families believed that their friends and acquaintances were aware of the cancer, whether they had informed them directly or not. The knowledge that others were aware of the diagnosis did not necessarily mean that the subject was talked about openly.

MC: Only two people I've told that I have cancer.
R: mm hmm.
MC: Nobody else. My wife told everybody else (chuckle).
FF: No. Not true. But our close friends know it. They come and drop in the same as they ever did before.
MC: Oh yeah well our...our daughter knows it and everything like that, you know, but....
R: mm hmm. So people know about it but you don't um...go out of your way to talk about it. Is that what you're saying?
MC: No way! I never discuss it.
R: You don't.
MC: No. Not with anybody.

One man described his opinion of why families living with cancer might prefer not to discuss it with people outside the family.

MC: But we...did find that people don't like to talk about it. There's a lot of people keep within themselves and they do not like to talk about it and they're quite worried about it.
R: These are people that have cancer and don't talk about it?
MC: They are people that have...yeah, that have cancer, yeah. We had one in here. The family didn't care too much to talk about it because they figured that he was...you know, bad enough that he had it.
R: So what's...why do you think people don't want to talk about it?
MC: Fear. The biggest factor is fear in people.
Several families described untoward reactions from other people as a factor that inhibited them from discussing cancer.

R: How do people in the building react when you tell them you have cancer?

MC: Oh...some of them look at you with a long face, but, I mean, you meet all kinds. See I'm used to all kinds. I've had 'em from the top up...the bottom down.

R: Do you find that you talk with friends or family or other people about your cancer very often?

FC: Uh...no. I don't think they like to listen.

FF: I don't mind.

FC: Yeah. Yeah, well just with her but not with friends.

R: mm hmm. But with your [family member] you can talk about it.

FC: Yeah. We talk, yeah. Friends I don't really talk to them. They feel sorry for you.

At times, these untoward reactions were not merely unsympathetic but were perceived as alienating experiences.

MC: I think the biggest problem you find when you're talking to people is that cancer is such a word that it scares everyone. And I've had this happen to me...I've told many people about it. It's amazing when you stand talking to somebody and in the course of the conversation it comes out that you have cancer...it's amazing...within a matter of a second, they'll take a step away from you. It's just unbelievable. And it's only because I think in the back of their mind, it'll jump to them. (chuckle) I don't know why. It's the only thing I can think.

FF: I've...I've told...I went to my old dentist, like, to have my plate fixed. And he's an older fellow. He must be close to eighty. And he has heart trouble. And oh...I thought to tell him wouldn't mean anything to him, you know, being an older fellow...they don't seem to react the same. And uh...so I thought, "No, I'll wait till he's finished the job and then I'll tell him." Like, I'm limping now...well before I never limped and he was sort of looking at me and he never said anything. But um...anyway, I told him uh...the last
appointment, I told him. And you know he just about threw my teeth at me and disappeared out of the room.

The perception that some people might react to the cancer in a negative fashion was expressed as a concern by most of the families.

FF: I don't know who...who should be communicating um...whether, you know, I should be communicating or...with people and say, "Look," You know. Maybe it should be that way. Maybe I should be saying, "Would you like to come over for coffee with us?" you know, so that they realize that [he's] quite capable to get out and go out. Maybe perhaps people, not knowing what's going on. Maybe that's part of the problem with uh...you know, as far as friends and acquaintances are concerned.

In spite of the perceived risks inherent in openly discussing the presence of cancer in their family, most of the participant families had done so.

R: So it sounds like you're not only willing to talk with all your family about it, but you would really rather everybody did talk about it openly.

MC: Yeah.

FF: Oh yeah. I told the ladies up at the church.

FC: I don't think it's uh...something you have to sweep under the rug. It's here. They're making great strides in it. And I think uh...the more people know about it, the better it's going to be for everyone.

Although such discussions were often described as difficult experiences, the families perceived them as ultimately beneficial.

MC: You've soon found out who your friends really were and thought something of you.

MF: So then by like talking to people about it and like you find out that there's a lot of people that have been helped by it.

R: mm hmm.
MF: Or have been helped to overcome it. They live, like, a normal life.

While most of the families found it helpful to have their friends and acquaintances aware of the situation they had encountered, and many discussed the cancer experience openly in their social worlds, there seemed to be a natural limit to the benefit of such discussions. With the urgency of the telling process completed, several families expressed the desire to move on to other subjects.

FF: I knew we had to do it to start with. You might as well get it over with 'cause they want to know. After that, you know, I'd rather sit down and play card games.

The pleasure associated with talking about something other than his cancer was described by one of the patients.

MC: We never talked about me at all. We talked about him and his hip replacement and all that. I told [my wife], "Boy is it nice to go and visit somebody and you don't have to spend 20 minutes explaining how you feel." I really felt good about that.

Clearly, deciding who to inform about the cancer, and how cancer discussions should be managed, was a common theme expressed by the participant families. A second theme that emerged in relation to their social networks was that of hearing others' stories about cancer. Although some of these cancer stories reflected the experience of people who were known to the families, many were about people the families had never met. As the stories themselves were passed on to the researcher, they were frequently prefaced with an explanation of their origin.

MC: My sister...she had a friend...her daughter got cancer too. All the participant families told the stories of several other people's cancer experiences during the process of constructing their own accounts.
Many of the stories they retold had been passed on to them by friends and acquaintances during the process of informing their social worlds that they were now living with cancer. Such stories were generally described as being negative in nature.

FC: Everyone...because of ignorance...everyone knows somebody who knows somebody, and they all had an awful experience.

FF: "Oh I have a friend," and off they go and it's always the gruesome details.

While families did not interpret such stories as factual representation of reality, they did describe a process of continually comparing the stories to their own experience.

FC: But you know when I hear of other people...I actually have not been with somebody that has been uh...violently ill after the chemo. That's what I was saying to you earlier...the last interview. You...everybody knows somebody who knows somebody etcetera.

R: mm hmm.

FC: But uh...I have not personally been with a cancer uh...patient that has been ill after chemo. I've only heard of them.

Several families talked of evolving past the point of being willing to listen to the stories.

FF: Well just mention chemotherapy. Just say chemotherapy and right away they are going to tell me all the terrible...they had a friend and she lost her fingernails and oh! And I just, you know, I just say, "Ok. Um...I'll cross that bridge when we come to it. I just don't want to hear that sort of thing." But I think that is being very insensitive.

MC: I'm feeling good. I'm looking good. That's what I want to talk about. I don't want to talk about your Aunt Suzie that, you know, her hair fell out and her arms fell off and her legs fell off, right? I don't want to hear all that nonsense. You know I don't want to dwell on that.
MC: They don't realize that that's not the kind of thing a person that's got a problem needs to hear, you know. If somebody's got some kind of disease or..."Oh well I had a friend who had the same thing." You don't really need that.

Although most of the families perceived themselves to have been bombarded with predominantly negative stories, one participant reported that listening to the stories had also yielded optimistic rewards.

MF: Hey, how can I put this? Like the stories that you do hear when like nobody in your family has cancer are the ones that are the bad ones.

R: mm hmm.

MF: Like people who have cancer and they suffer through it...the whole thing...and then eventually just die.

R: mm hmm.

MF: But when somebody has it, then you find there are a lot of people that...even friends...who have it or somebody in their family has it...and they're doing fine.

In general, the families in this study described the storytelling of others as a common experience in their everyday lives. The potency of these stories was reflected in the frequency with which they retold them to the researcher in the course of describing their own experiences.

Communication in relation to cancer occurred not only with friends and acquaintances, but also within families themselves. Some families perceived that the physical symptoms associated with cancer and its treatment created some disruption in their usual communication patterns.

MC: If you constantly feel groggy and dragged down and tired, you're irritated or you're uh...unsteady, well you're liable to say things you don't mean to say like hurt uh...offend each other.

R: mm hmm.
MC: Unknowing that you've doing it even and not realizing that you're doing it until after it's done.

R: mm hmm.

MC: And it's not something that you mean to do but it's just that your health isn't up to par and you don't realize until after you've done it that you shouldn't have said what you done or you shouldn't have done what you done.

Families also described various means of communicating when a member was feeling particularly depressed.

R: What do you do when you get down in the dumps...or does that ever happen?

FC: Oh yes. It happens. Oh I...my old fellow's good there (laugh). He's very helpful.

R: What does he do?

MF: Who me? Young fellow? (laugh)

R: Yeah. This young person.

FC: Yeah.

R: What does he do that...that helps in that situation?

MF: Oh...comfort her.

FC: Yeah, he's very kind.

R: So do you have to work to help [wife] stay not depressed?

FF: (laughs)

MC: Oh I do. I do. I say, "Oh you ain't gonna put me in a pine box. I'm gonna stick around and give you a bad time too."

FF: (laughs)

MC: Oh yeah. You ask her if I ain't got a sense of humor. You ask her.

FF: I know that.
MC: She worries but I don't. I don't let her worry.

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R: Well since you...you've had your illness, have there been any times within that...like the time that it was diagnosed, or times of treatment...that have been particularly upsetting or disruptive to your family life?

FC: Oh, time I say thinns and then get corrected. (pause) Not corrected. Just pointed out that...there's nothing wrong, don't worry about it, everything's all right.

R: So you've kind of got down in the dumps sometimes and....

FC: Just a little bit. Nothing really.

MF: She better not get down in the dumps, 'cause we're gonna beat this. She's gonna live...we're both gonna live a long time.

R: So your job is to make sure her attitude stays positive. Is that right?

MF: Absolutely.

The families varied considerably in the style with which they chose to communicate or not communicate the emotions they experienced in relation to the presence of cancer. Half of the families indicated that they did not openly communicate their sadness or worry with each other.

MC: My uh...my only concern is my wife. That's my only concern.

R: Your concern's your wife.

MC: Yes.

R: mm hmm.

MC: Not with myself.

R: mm hmm.

MC: And her concern is me..I believe. But you can tell her what your concern is.

FF: Well that's it, but I don't show it.
Families who did not tend to express their emotions openly in their everyday lives behaved accordingly in the research interview context. In two instances, however, a family member left alone with the researcher for a few minutes acknowledged an awareness of the partner's feelings, which had not been openly communicated.

MF: A while back you were asking about mother breaking down, eh? Well, she's more or less kept that to herself too.

R: And that's...that's her way of doing it.

MF: Yeah. I caught her a couple of times. How often it's happened I don't know.

FF: I know if I'm crying or...inside...I never show it to him. I do that privately.

R: You do that privately.

FF: Yeah. And I think he does too.

R: mm hmm.

FF: Yeah.

R: Kind of an unspoken agreement?

FF: Yeah. Yeah. Just something that we don't show.

These private "confessions" to the researcher seemed indicative of two phenomena: firstly, that the need to portray the experience accurately was greater than the need to maintain family secrets; and secondly, that the cancer experience as articulated by family groups might well differ from that articulated by the individual members separately.

Families who described themselves as being open in their communication of feelings perceived this as an advantage. As one family
member declared, "I think it's brought us a little closer." One patient described realizing the importance of this openness when a secret he had held produced family conflict.

**MC:** So I didn't tell her, and so...and then I learned my lesson. From now on, I tell her everything no matter how bad or how good, I tell her anyway.

Several of the families expressed the opinion that sharing information within families was also an important communication issue.

**MC:** I don't believe in hiding anything from them. If the doctor tells me I've got, you know, six months to go, then I'll tell my kids. Cause I think it's important that they know. It'd be much easier to handle than it is if all of a sudden you say, "Oh hey, I'm real great," and then tomorrow it happens you're gone. That's too hard on people.

**R:** Secrets are a really big pressure, aren't they.

**FF:** Oh yes.

**MC:** That's right. That's right. And as I say, I don't think there's any need for it. I think you should be open.

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**R:** So it sounds like the openness about cancer and treatments has gone right down to the grandchildren.

**MC:** Oh yeah. Yeah. Oh they were...they weren't told that I may die or anything like that. That grandpa was very sick and the doctors had to do this and had to do that, and things like this, you know. And uh...grandpa's gonna have some treatments and he's gonna lose his hair.

Thus the families differed from each other in the communication style they used in relation to the cancer and its emotional impact. Discussing cancer within the family was not necessarily valued. One family explained that the usefulness of talking about cancer-related issues had diminished over time and had been surpassed in importance by the need to focus upon other aspects of their life.
MC: I think most of the time we ever talk about it is when I go for my treatment and I just say, "Hey."

FF: It really is, isn't it. I want to know what happened, and...

MC: You know...they boosted my shot again this week and the good wife says, "Uh oh. Tomorrow you're going to be twice as sleepy," and I say, "Yep." But very seldom else do we talk about it, unless we have company over and they want to know what's going on.

Most of the families who participated in this study did not perceive cancer to have had any major impact upon their usual communication patterns within the family.

FF: It won't be a drastic change, believe me. If you don't get along with somebody else before you're sick and all of a sudden you're sick, how are they going to get along with you?

FC: mm hmm.

They did, however, describe incidents suggestive of some communication changes with the family.

R: So do you think making up with your brother had anything to do with your illness? Do you think you've changed toward him in any way?

MC: Well I look at it this way. There's no use holding a grudge all our life.

FC: The children have made no difference whatsoever. They still...like I think I would be different if it were my child. I don't think I would have it kiss grandma. Like I'd tell...teach my child don't kiss her on the mouth or...you know...where it's me that makes sure that my grandchildren don't kiss me on the mouth anymore. Like...just...I turn my face and then I kiss them on the forehead or...you know.

R: mm hmm.

FC: But the...my own children have not instructed their grandchildren...their children to be any different.

R: mm hmm.
But uh...I...I imagine they're glad when they see that I don't...you know. You're always afraid. You can't help wondering if it can be transmitted...transferred, eh?

It appears, therefore, that the presence of cancer in a family member had an impact upon the family's communication in a variety of ways. Decisions regarding who to tell, what to tell, and how to tell confronted all of the participant families. Once friends and acquaintances were informed of the presence of cancer, the families were treated to a barrage of cancer stories, most of which were unpleasant and distressing. Finally, families had to communicate, overtly or covertly, information and feelings between their members.

Impact on philosophy

All of the families who participated in this study were aware that the diagnosis of their ill member was cancer, and that cancer is a life-threatening illness. Most of the individuals with cancer had a metastatic form of that disease. Although none were expecting imminent death at the time of the study, and the prognoses they had been given were varied, none were expecting a complete cure either. In fact, two of the cancer patients died within three months of their participation in the interviews.

A common theme in the experience of these families was that of searching for reasons why cancer had struck in their midst. Several families described the feeling of unfairness that their member had been afflicted while people who made no social contribution were spared.

You say to yourself, you haven't killed anybody, you haven't killed ten children...you haven't killed six people, burned them up...you haven't stabbed anybody. And you spent hours
and hours of laboring to help other people... I could name you different occasions, but I won't go into it. I say to myself, "Why?" You know, you can't help it.

R: Do you say it out loud or....?

FC: Oh the odd time.

MF: Oh she gets a little bit upset sometimes and I tell her I know why she gets upset because of how much help she's given to people, or how much help we've given to people.

FC: Right.

MF: And uh....

FC: Why should I get this?

MF: Then we look at....

FC: Other people don't do anything for anybody.

MF: No, and then we look at other people that are murderers and what have you, and rape artists and....

R: mm hmm.

MF: ...child molesters and everything else, and then we say to ourselves, "Well why doesn't this happen to people like that?"

R: mm hmm.

MF: I mean we ask ourselves that question.

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FF: I can't explain it. I'm no superhuman person, and there are times...I won't say I question why it's happening...I don't know why it's happening to someone as terrific as [my husband], I really don't.

A letter from one of the grown children living away from home expressed a similar sentiment.

FF: "Why my mama!" was my initial reaction to the news. The word "cancer" to me is associated with excruciating pain and approaching death. I thought that if fate was fair it
would've chosen someone old and miserable just putting in time in a nursing home, not my cheery, loving mama.

The questioning that occurred in reaction to the presence of cancer was also expressed in a more general manner.

MF: Like you hear of people getting cancer and everything else, and then when somebody gets it, then you start realizing that uh...that anybody...nobody's immune.

In several families, the experience of unfairness was expressed as a sense of suspiciousness that someone somewhere must be responsible for the blow that had been dealt the family.

MF: There's like this thing where like after I saw that one program and talking to [a friend]...there's that...he was getting pissed off.

R: mm hmm.

MF: Because like they're so close. And then it seems like the government doesn't want them to find out, 'cause that's...I guess that's the number one fear...of uh...humans...is cancer, because there is no cure. And so through that the government can bring in a lot of money.

R: mm hmm.

MF: Like through donations and whatever. And if they find the cure, then they don't have any.

The process of questioning appeared to generate a considerable degree of distress in many of the families. Accepting the fact that questioning was futile was described by several families as an alternative to experiencing that distress.

FF: But it's just...it really is a matter of accepting and not questioning. Because questioning isn't going to do any good...to keep going on, "Why should it happen? Why?" It doesn't help.

FF: I guess it's just no good questioning, 'cause nobody knows why these things are happening.
A second theme associated with family philosophy was that of acknowledging the patient's possible eventual death. In describing this experience, the families tended to refer to terminality as a possibility, and not as a certain outcome. Sometimes the threat of death was hinted at in the course of constructing the accounts.

**FC:** I had great hopes that I would live long and a good healthy life.

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**FC:** I want to live just like everybody else. I want to stay here...with my family.

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And in a letter:

**FF:** We can never forget she has the disease. It's as if there's a big, black cloud over our heads and one day it's going to burst and our lives will all change.

Other families acknowledged the presence of the threat indirectly by denying that it had impact upon their lives.

**MF:** We're gonna beat this. We're gonna live a good life. We got years and years together yet, and that's the way I look at it. And if I look at it any...from any other different point of view...uh...I'm uh...I'm one of those defeatists.

When families acknowledged the spectre of death more directly, they did so with considerable emotion.

**FC:** Well...I feel angry that I have to go.

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**MC:** If I were to pass away....

**R:** mm hmm.

**MC:** (bursts into tears) How will she survive? That's my only worry.
FF: You don't have to worry about me. You just worry and take care of yourself.

MC: Oh bullshit on me. I made my peace with God, and I have my house in order.

R: mm hmm.

MC: Everything's all taken care of. So what the hell am I going to worry about?

FF: Be happy, that's all.

MC: I am happy.

Acknowledging the possibility of death lead to wondering when it might occur. An excerpt from a letter from a grown child illustrates this concern about the amount of time remaining.

FF: Even if the chemotherapy treatments give her a few more years it's as if her number has already been called and she's been able to delay going this time but what about next time?

Although most families presented a shared perspective as to what their futures held, there was evidence in some families that members did not discuss the possible terminality of cancer with each other.

R: What's the worst part of it then? Is it the worry or....

FC: I think so. In the back of your mind is always...when is it going to return?

R: mm hmm.

FC: It will return. You can't get away from that. It always does. It always has when people get it, you know. So you just think about when's the axe going to fall and you're finished then...you know...you're...that's it.

R: Do you both find that thought preoccupies you quite a lot of the time, or is it something that just hits you every once in a while?

FC: For me it's...I think about it quite a bit. What do you...? (to MF)

MF: It's not going to happen.
At times, family members seemed to surprise each other with the views they expressed during the research interviews.

MC: But if [doctor] has never told me to quit. Now if he said, "Listen, either you quit smoking or you'll be dead in a month's time," (pause) I'd say, "Let me go and think it over."

MC: And I would think it over.

MC: And I'd probably keep on smoking (chuckle). That's how much afraid I...that's how much fear I've got...of dying.

FF: Oh I think if they told you to quit smoking you would. You said you would. I think you would.

MC: Well what I said and what I'm gonna do is two different things. You know people say a lot of things and then they retract their statements.

In describing the experience of acknowledging the life-threatening nature of the illness, some families portrayed a view of the future that included a sense of preparedness for death.

MC: I don't want to think of all the things that can happen, 'cause maybe somewhere along the road it's going to happen, but...like...when it comes, I'll be ready for it.

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MC: I've been preparing for...to pass away...well, since I started line work.

MC: That's 35 years ago. There's no change in my outlook on life whatsoever.
Another experience associated with the awareness of mortality, which was suggested by some of the families, was a heightened valuing of life itself. As one patient explained:

**MC:** Unfortunately it sometimes takes an illness to really bring you to this...'cause most people you talk to, you know, they never think about what'll happen to me tomorrow. I mean we don't know from now till an hour from now what's going to happen.

He later elaborated on this experience.

**MC:** Well as I say, you know, life is so precious that when you think that somewhere down the road, you know, it's going to go. It's such a precious thing that...you know...as I said...it's unfortunate that we have to have illnesses to make us realize how important it is.

Finally, a few families were able to identify aspects of their life that had perhaps been enriched by their having to consider its ending.

**FF:** I think you're more aware of...I don't know...maybe the sun's sunnier and the flowers are brighter...and you're more aware.

**FC:** I think it draws you much closer. You know like uh...maybe you're afraid of tomorrow...a little.

The common experiences shared by these families, then, were those of seeking answers to unanswerable questions and confronting the eventuality of death. All had asked themselves why they were chosen to undergo this experience, and all had acknowledged, either directly or indirectly, that the experience might lead to death of one of their members.

Thus, although all families described changes in emotional state, roles, communication, and philosophy resulting from the intrusion of cancer into their everyday lives, they also persisted in expressing the perception that nothing had changed.
R: I was saying I was interested in what's changed, and you said, "Well, our life's ordinary." Can you tell me about that? What's ordinary about it?

MC: Well we live this very same kind of life as we did previously. We have no problems. We're not concerned about cancer.

FF: So we haven't made any change actually in...in our lifestyle at all. Just carried on.

FF: I don't really think it's changed that much really.

FC: Yeah. I don't think so, Sally.

FF: It's just another incident in our lives, that's all.

FC: Yeah. Something that...you know...you have to take it when it comes.

As families began to explore the shape of their cancer experiences in increasing depth, explanations of these contrasting realities began to emerge. The final two sections of this chapter address the explanatory layers of the families' accounts.

Explaining the Impact

The families explained the phenomena they had described in terms of choices and strategies. A discussion of these explanations will constitute this second section of Chapter 4. Within this discussion, the concept of attitude will appear frequently as a factor related to the explanations. Since attitude forms the focus for the third and final section of this Chapter, and provides a framework for integrating the previous description and explanation, it will not be addressed in detail in this layer of the explanatory accounts. Rather, this section will examine families' perceptions that they had chosen strategies for coping with cancer. It will further explore their perceptions that the success
of these strategies explained, at least in part, how cancer's potential impact on their everyday lives had been thwarted.

Their ability to maintain the quality of normalcy in the face of the disruptions resulting from the cancer experience was described by families as a product of choices they had made. They all believed that choices had to be made early in the cancer experience as to the strategies with which they would approach the impact of cancer upon their lives. The families perceived that the effectiveness of the strategies they had chosen accounted for the degree to which the presence of cancer had an impact upon the characteristic scheme of their everyday lives.

When one patient was asked about the contrast between the changes she had enumerated and her claim that nothing had changed as a result of cancer, she replied, "I choose to think there's no difference there." Many of the families perceived themselves to have made different, and better, choices than might others in a similar situation.

MC: That I guess is the biggest thing with cancer for most people is that when the doctor says, "Ok, well sorry, but you've got cancer,"...that's it. Life's over. That's it. Huddle in a corner and forget about it. You know that's gotta be...I'm sure it happens to a lot of people. Instead of looking and saying, "Hey. Okay, doctor, what can you do to help me? How fast can you do something so I can stay here for awhile?" I think...I'm sure that a lot of people just throw up their hands and say, "Cancer...That's it. The world's come to an end and that's it." And it really doesn't have to be.

One participant compared the opportunity for choice to the maintenance of a soldier's sense of judgment in battle.

MC: So it's the same thing in this cancer business. A lot of people lose their nerve and then they give up and they don't want to live. They don't care.
The belief that they had made appropriate choices was affirmed repeatedly during the accounts by families' comparisons of themselves to others.

MC: This is just one thing that you accept, and you go along with it. It's all part of the game, you know. That's why I don't have patience with people that panic.

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MC: Well we uh...we don't have much patience for people that have self-pity.

References to the global "they" occasionally included examples from the collection of cancer stories that had been acquired. More often, however, "they" seemed to represent a general perception of how humanity at its worst was inclined to react to given situations. Throughout the construction of accounts, all families referred repeatedly to the behavior of the perceived "they" to contrast it with their own approach to the experience of cancer.

When families articulated the major choices they had made, it was apparent that they were referring to abstract approaches rather than concrete tactics in the management of everyday life with cancer.

FF: It's up to you whether you want to do it or not. You have to realize that you want to do it and you need to do it. And it's all up here (points to head). You know...how you think....

FC: Yup.

FF: ...and how you feel.

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FF: It's mind over matter. Whether it's true or not, you know, you can prove it right here and now.

The importance of having some sort of cognitive strategies was a theme common to all of the families.
MC: And there's nobody can change it...once you have it, you have it. You have to overcome it by your attitude.

Although families perceived themselves to have made conscious choices in their approach to the cancer experience, they described these choices as logical and natural events, rather than the fruits of intensive decision making.

FF: I just thought of something. After [my husband] had his...it was after his colostomy, and we went down and saw [the doctor], and I remember coming out of [the hospital] and [the doctor] said, you know, quite plainly, "It's...you know...I can't guarantee there's anything cured, or whatever." I can remember walking out. Do you remember getting in the car and I was driving 'cause it was just after you came out of the hospital? And I remember turning to you and saying, "I don't know what it's all about," and I was crying, "but we're going to make the best of the days we've got." Do you remember that? And I thought of that several times, 'cause we sure have, haven't we?

Much of the explanation for the impact of cancer upon the family's everyday lives was expressed within the context of describing specific strategies with which they had approached numerous facets of the cancer experience. The following exploration of the families' accounts of their strategies illustrates both the location and the nature of the choices they made. For the sake of a coherent portrait, these strategies have been grouped into four broad categories: adapting everyday life, creating a network, managing medical care, and generating hope. This categorization of the strategic choices described by families does not presume to imply any specific order or magnitude to the strategies. Rather, it attempts to link together related themes within an integrated whole in order to facilitate presentation of the explanations as they were constructed in the families' accounts.
Adapting everyday life

The strategies for adapting everyday life were those that addressed the management of the instrumental and emotional activities of the families on a day-to-day basis. As has been described previously, symptoms associated with cancer and its medical treatment were experienced by all of the families. One strategy used by several families to minimize the impact of such symptoms was to "look on the brighter side of things." Where prior physical abilities had been lost, families attended to the abilities that had been retained.

FC: Some people don't understand it. How come I'm not bitter I have to go and use a cane now. I say, "I'm not. I'm thankful I...I can still walk around." You don't take that kind of attitude. That's no good. Then you resent and you hate everybody. Grow to hate yourself in the end, too. That's crazy. There's no need for that.

Most of the families felt strongly that a cheerful and positive approach not only reduced the distress associated with symptoms but also prevented them from occurring. When discussing nausea resulting from chemotherapy, one woman said, "I have found that it's the very hyper, frightened person who becomes ill." In explaining strategies conducive to symptom management, the following opinions were expressed:

MC: I said the only thing is be cheerful...you'll be tired, you'll be depressed lots of times, you won't feel like eating, you'll feel nauseated, you'll feel like vomiting. But the thing uh...in the process is to eat well and take your treatment regardless if you lose so much food from the vomit...wash your stomach out uh...with water and that...you know, drink water and that...and uh...keep eating. That's the main thing.

R: mm hmm.

MC: Don't give up and say, "Well I feel sick. I know this, I know that. That's the worst thing you can do."

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MC: But uh...I mean I didn't um...lay in wait to see what was going to happen...like when's the sky gonna fall in.

R: So you really felt your attitude toward it had a lot to do with keeping the symptoms away.

MC: Yeah, I think so.

Most of the families were convinced that their beliefs and attitudes toward actual and potential symptoms had an impact on their experience of symptoms.

The uncertainties associated with the cancer included, for these families, some difficulties predicting the well-being of the patient on a daily basis or in the months ahead. Many of the families explained that they had evolved a strategy with which to deal with planning. The strategies that were described varied considerably. Some approached the problem by not planning anything very far ahead of time.

FC: So you have to sort of plan day to day. Where if you don't know you have any kind of disease or like if you don't have cancer you plan your future, which we had, you know, all planned out for when you retire.

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R: Do you find that you plan things differently?

FC: Yeah. Yeah. So I don't plan (chuckle).

R: You don't plan things.

FC: No. No I don't have any plans. Just get up and go when I feel like it.

R: mm hmm.

FC: Yeah. No use to plan. Even the people that are well, they still plan and they still...but something goes wrong.
Families who had adopted this strategy argued its appropriateness in the sense that the future is unpredictable for everyone, ill or well.

FF: You know, really, I think maybe this is one of the things that I keep thinking about is...I don't know...nobody knows what tomorrow's going to hold, and if we can keep that in mind and remember that...it's not easy. I'm not going to sit here and say, "look it's a cinch," 'cause it isn't. I just have to keep reminding myself that...one day at a time...or a couple of days. Let's just plan for this weekend and not worry about three months from now, you know.

FC: You can't plan it. Maybe you shouldn't feel that way because you never know at...when you're in your sixties you never know what's going to happen anyway.

Other families minimized the feeling of uncertainty about their futures by refusing to allow cancer to have an impact upon the way they planned their lives.

FC: I don't know uh...I say the long range uh...I have...uh...I haven't put a time limit on what the long-range period might be. I just don't think that way.

R: mm hmm.

FC: As long as I feel good, I'm...uh...I'm not making those kind of plans.

FC: I've always been a little more careful with the dollar than some of the rest of the family, and uh...[relative] will say to me...has said to me more than once, "If you want anything, go and get it. Don't just save it,"...and you know...which sometimes I wonder if she thinks the long range plan might be a short-range plan.

FF: (loudly) No I don't!

FC: And uh...but no, no I don't uh...assume for one minute that uh...I might be sick next week or the week after that and I must do this differently or...and that differently. Not at all.
One family's strategy was to continue making plans, but to consider these plans as enjoyable fantasies rather than certainties.

MC: We make plans, but we don't say...um...this is an obsession with us. No way.

R: So you enjoy the fun of checking out the various plans and....

MC: Oh hell yes.

Another family described their approach as planning further ahead than before they had cancer.

MC: And we sort of um...plan farther ahead.

R: You plan farther ahead?

MC: Oh what we are going to do. Because like uh...you get that sword hanging over your head...not the fact that you're expecting it to fall any day, but uh...like uh...I would say like my reserve strength...I haven't got what I had.

The potential for transforming the uncertainty into a motivating factor was hinted at by a number of families.

MF: You get a...better outlook on life as far as like um...not putting off things you want to do.

R: mm hmm.

MF: That's like if you want...like...well I've never travelled, and like...everything that's happened...I figure if I don't do it now then I might not get a chance.

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FF: But it's just little things like that. We just...other times, you know, we've got up and there's things to do and then by the time the day's over we always said, "You know what we should have done...we should have done this."

R: mm hmm.

FF: Now we're doing it.
Although families employed a variety of strategies toward planning, all perceived the strategies they had adopted to be realistic and effective tools in minimizing uncertainty about the future.

Despite vivid description of physical trauma, emotional turmoil, and existential doubt, the families tended to emphasize the positive aspects of the lives they were leading.

R: Well you both certainly seem to be people who enjoy life a lot.

FC: Yes we do. We uh...I think uh...I could be far worse off than I am.

R: Well I'm just...I think the story you've told is very impressive. You've been through surgery, and three radiation courses?

FC: Yeah.

R: And now chemotherapy.

FC: Yeah.

R: The big three kinds of treatment everybody talks about....

FC: mm hmm.

R: ...as if they're so horrible.

FC: Yes.

R: And you're still telling me that life is good.

FF: Oh yes.

FC: Oh I should say so. Good heavens, yes.

What the families were clearly declaring was the value they placed upon normalcy in their everyday lives. The criteria used to evaluate normalcy were peculiar to each family. Within this context, none of the families used illness factors as measures of the degree to which their
life was normal. Rather, each articulated a unique yardstick that had significant meaning for that family. In one family, the husband's ability to continue going on fishing trips in spite of having to leave his ill wife at home was the yardstick for normalcy expressed by both partners. In another, the fact that the patient was able to continue working was a criterion for normal life. A third family, when asked what was normal about their life replied, "We still drink and smoke." Other families expressed their concept of what makes a life normal in a variety of ways.

MF: I mean domestically-wise...companionship-wise...uh...living-wise...uh...our whole life is just the same as it's always been. There's very little change there. We have people...we go out and play cards with them. They come down here and play cards with us.

MF: [If I didn't have cancer] the style would be the same. I still like people even though...even with the cancer. I mean I never let it bother me...go around and say, "It's too bad. It's too bad." Even my aunt said, "Oh I hear you've go that dreadful disease." "Oh," I said, "I'm still here." (chuckle)

FC: [My doctor] finally allowed me to go back to playing a bit of golf as long as I don't overdo it. And to me that was a great plus, 'cause, you know, there was a day when I thought I'd never do this again, yeah?

MF: Before mom had cancer...like we've always been a close family. And as far as um...like getting together a lot of times or just coming by to visit. And when we found out mom had cancer, like it wasn't like we'd get together just once in awhile or once in awhile. 'Cause if like...for every...just about every occasion plus birthdays...like everybody gets together and comes here. So as far as that goes...like nothing's really changed.

MC: Like I say, we've been to Reno twice in December.
R: Yeah. Twice?
MC: So I mean...yeah, twice in December.
FF: Oh yes.
MC: So I mean uh...'cause we both love gambling.
R: mm hmm.
MC: That's part of my nature. We used to have gambling games here every Sunday.
FF: Shhh! Shhh!

These criterion references in part explained the discrepancy between how the families described their everyday lives in relation to cancer and how they evaluated that description. Although families were aware that aspects of their lives might not appear normal to an outsider, they used their own set of criteria to define normalcy in their everyday world.

Role-function changes were discussed earlier in this chapter as a feature of the cancer experience. The fact that role shifting had produced minimal disruption in most families was explained in the construction of accounts. In terms of instrumental roles, families tended to balance the impact of role losses with the role retentions and role acquisitions. In addition, all of the families had preserved the emotional roles of their members. Many of the participants were able to provide a clear description of the roles they played in the family emotional dynamics.

FF: Oh I'm the leveler I suppose.
MC: Oh yeah.
R: The leveler.
MC: She's a good leveler.
R: There would need to be one I guess in a family of so many determined people.

MC: She can slow us all down.

FF: Well, I'm too slow to start with (chuckle).

R: So you keep them all sensible. Is that your job?

FF: Well I try to...to calm the storms when they come up. That's about the only thing I could do.

None of the families in this study had permitted the characteristic direction of emotional support to be altered as a result of the presence of cancer. Where the cancer patient had fulfilled an emotionally supportive role prior to the onset of cancer, he or she retained that family function when ill.

FF: I'll tell you what. [My husband's] like um...a little like a doctor, but he's a person. I never told him this before. He's like a person. He'll help you out, you know, whether you have problems or anything else.

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FF: I can get all ranty and ravey, and [he's] a terrific listener. I mean I never get annoyed at work, I come home and get annoyed. And then I'll lay in bed and think...I don't know why...it isn't that important anymore...and that helps a lot. Even just in my everyday frustration.

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FF: [She] would set the pace for our feelings, you know. If she were...uh...the type of person that would...uh...wallow in self pity or something like that, I suppose we'd have to change our attitudes to compensate or whatever.

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FF: I would be very much more depressed and probably stay depressed if [his] attitude was different. It's his attitude and strength I'm sure that uh...brings me along.
Thus the families minimized the impact of cancer upon their role relationships by acquiring and retaining instrumental roles, and by preserving their characteristic emotional role structures.

"Sticking together" was yet another strategy used to approach the cancer experience. Many illustrated the importance of this strategy by relating cancer stories in which family break-up had been triggered by the diagnosis of cancer in one of its members. "Sticking together" seemed to imply sharing the repercussions of cancer within the family group.

MC: I think that's important too that...that you stick together when you're going through something like this. You've got to have somebody to stick together with you...to be alongside of you and uh...it's nice to know that somebody worries about you. You know, I tell her not to worry, that...you know...things are going to work out okay, but we're all human and we all have to have a...you know...we're all going to worry a bit...no doubt about it.

For some families, "sticking together" meant maintaining open lines of communication.

R: How does a family do that...stick together?

FF: Well...I'll tell you one thing is uh...they gotta live together and they gotta....

MC: Learn to share together.

FF: ...share together and everything else.

MC: Share their feelings.

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MC: The biggest thing in a family...facing cancer...is being open with one another. Very open.

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MC: I think a lot of people have this problem is they just...you know...they don't like talking to their partners about it. But then I think that's wrong. I think it's so wrong. You've got to share your problems, you know, 'cause it's a big
undertaking to...to carry it with you all by yourself. It really, really is.

Several families perceived the freedom to openly express emotions as a significant aspect of sharing the experience as a family. For these families, being able to cry in the presence of other members was expressed as a significant coping strategy.

MC: Maybe one thing too...that we're very close and we can cry together. And that's a big relief. I went to see [the doctor] last week and he said, "Hey. You look so good today," you know. "What happened?" I said, "I'll tell you what, doctor," I said, "I...my wife and I had a good cry on each other's shoulders last night. We really had a good cry." And he said, "That's super." He said, "If more people could do that..." It takes the pressure off people. And we've had three or four good, you know...just emotions that were pent up.

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MC: You know, most men say, "Yeach. I can't cry," and that. That's a bunch of nonsense. You know...let yourself go and have a good cry. It doesn't do any harm. It doesn't...it doesn't make you any less of a man...crying. I don't care what anybody says.

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The meaningfulness of being able to cry was illustrated in this defence of the strategy by one family.

MC: Well there's things that people say to [my wife]. "Now whatever you do, don't cry in front of [him]."

FF: Oh yes.

MC: "Now don't upset him."

R: You've had that advice, have you?

FF: Oh yes. I've had it.

MC: Oh boy I'm telling you...don't let me hear them telling you that.

FF: I have had...well-meaning people....
MC: I said, "I'll put them in their place." I want her to cry. I don't care if she cries in front of me. I want her crying if she feels like crying. I want her to cry.

On the other hand, not all of the families perceived open expression of emotion to be a productive approach to living with cancer. As has been mentioned earlier, several families explained that although they did experience emotional upsets, they chose not to express their sadness, fears, or worries to each other. Many of these families openly acknowledged the fact that they hid emotions from each other, and expressed this as a shared strategy within the family.

FF: Uh...well you worry about the person.
R: mm hmm.
FF: But you try not to show it ever.
The fact that they were able to explain this to the researcher in the context of a family group interview suggested that they perceived their lack of open communication to be a family style or strategy rather than a family shortcoming. Thus the participant families described both expressing emotions and concealing emotions to be effective strategic approaches, in keeping with their own characteristic styles.

The final theme associated with adapting everyday life was that of utilizing strategies to circumvent worry and self-pity.

FC: I am uh...the cancer...uh...say, victim. That's not a good word but...I'm the one with the cancer. Well if...if [relative] was worrying and stewing, you know...and different people around me worrying and stewing and watching my every move um...naturally it would reflect in...in my attitude toward it.
R: mm hmmm.
FC: And then if you were a certain type...uh...you would uh...all of a sudden start feeling sorry for yourself and
these...perhaps aches and pains would really manifest themselves and um...so I do feel that it's the...a lot to do with the people around you and...and their approach to it.

Worry and self-pity were viewed as major demons threatening families living with cancer, and most families possessed cancer stories that illustrated the nature of the threat. The stories emphasized the need expressed by these families to find strategies to avoid worry and self-pity.

MF: What's that...what do you call that? A fatalistic outlook? What's gonna happen's gonna happen.

R: Worrying about it doesn't change things.

MF: No. Only drags you down.

FF: I just...I can't understand people who can sit and...and uh...worry and worry and worry and worry and worry about themselves. It's sort of...in a way it's selfish isn't it...you know, to keep on stewing and stewing.

Humor was mentioned by several families as a means of overcoming worry and self-pity.

MC: People that are funny, they're more apt to fight it and get over it, because the simple reason is they don't let it get em down to worry. Stress is one thing that is the worst thing you can do.

Many of the strategies described had to do with not dwelling on the subject of cancer.

MC: The main thing is for people when they got cancer is to forget about themselves. Carry on as if nothing happened and they haven't got it.

R: Carry on as if nothing happened and they haven't got it?

MC: That's right.

R: Is that possible?
MC: Yes it is possible. Very much so. How do you think I got this far in two years?

FC: We just don't sit around and discuss our ailments.

R: mm hmm.

FC: There's so many other interesting things.

This strategy, common to most of the families in this study, did not deny the presence of cancer, but focussed attention instead upon the issues and activities associated with living in the everyday world. Maintaining involvement with people and activities was a frequently mentioned strategy for preventing worry and self-pity.

FC: I think a lot of people, they...they're by themselves too much and...and then they turn inward. They get feeling sorry for themselves. And this causes a lot of problems.

R: mm hmm.

FF: 'Cause they can't cope with pain.

FC: They just can't cope with it and as I say, if you sit and...and you got a little ache and you're by yourself...then all of a sudden that ache is a dreadful pain.

FF: It's just...just the little things that are...I mean if keeping busy...I think that's a big thing. I think if you can keep busy and make a point of like getting up to the Metro Theatre and Studio 58. Just...I don't know..just being involved, I guess.

The families were unanimous in their perception that keeping busy was a key strategy in successfully managing the cancer experience.

MC: Well if you're not busy, then you just sit down and what do you do? You think about your problems.

FF: Well you dwell on it. That's the trouble.
MC: And that's all you think and talk about. It's...you know...it's bound to drag you right down hill. If you keep yourself busy, Man you haven't got time to be down.

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MC: If you sit around and watched the clock go 'round you'd never get anywhere, right?

The strategic approaches adopted by these families to adapt everyday living to the presence of cancer, then, included: formulating beliefs with regard to symptoms; finding ways to plan that minimized the uncertainty of the future; evaluating normalcy according to unique criteria; preserving and maintaining family role relationships; facilitating family solidarity through expressing or not expressing emotions openly; and, minimizing worry and self-pity by keeping busy, involved, and active. According to the families, the successfulness of the strategies they had chosen was reflected in the normalcy with which they were able to live their everyday lives. While some strategic approaches were shared by all families in this study, there were several instances in which contrasting approaches had achieved equally successful results.

Evolving a network

The second group of strategic approaches articulated by the families to explain their experience revolved around the central theme of evolving a network. The social patterns of most of the families in this study underwent some change as a result of having cancer. Families perceived their social life to be a significant aspect of their everyday reality.

FC: But I had started...uh...more ever since my mother died... uh...to try and get out more with my friends and...you know,
meet them down town and get out of the house a bit. But now that's ended.

When changes were identified, many families attempted to formulate an understanding of the phenomenon.

MC: And uh...we often wonder is this why people...you know...hesitate having you into the house type of thing. Cause they're scared what you're bringing in.

R: mm hmm.

MC: And they don't like to say anything, but uh...they really don't understand. And if you don't understand it, you know...something about cancer...then it is a scary thing I'm sure.

Many of the families described strategies they used to facilitate the retention of the social worlds they enjoyed prior to having cancer. Several felt that the attitude with which you approach others was a key factor in their response. Being cheerful and positive was one such approach.

MC: As you say...other people. I don't mind telling them if they ask me how I'm doing...I have a tendency to say, "Hey, terrific." My wife says to me, "Would you please stop saying terrific, 'cause you're not terrific." And I say, "I know, but I hate to keep, you know, I hate saying anything to somebody that" ...oh well. So now I find it's... I just say, "I take one day at a time, and I enjoy it." And uh...'cause I want to be positive about this thing you know.

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FC: I think people get tired of you crying too and uh...you know, they might stop coming if you start complaining a lot or...your family might decide it's...you know...no pleasure visiting, you know.

R: So it sounds like you've made a decision to avoid complaining if at all possible.

FC: Uh...yes. Yeah.

R: mm hmm.
FC: It's not going to do any...make any change is it.

Letting others know of the limitations and capacities of the family in view of the patient's physical condition was another strategy used by all who attempted to maintain social relationships.

FF: And this is what I'm saying to people...you know..."Don't ignore us. Certainly while we're able...have us over...just to come for coffee."

Central to maintaining old friendships throughout the cancer experience was the skill of addressing and minimizing the fears others might have about the disease.

R: It must be difficult trying to live your...treat your social life normally if people are acting a bit peculiar.

FF: Yeah. It's extremely....

MC: Well you have to sit down and explain it to them. We do this. We'll talk to our friends and we'll say, "Now look. We want you to understand what's going on, okay? And don't be scared because, you know, there's nothing that'll jump from me to you and you're gonna end up with cancer...and that doesn't happen. And you have to end up explaining to your friends. And then from then on you really don't have any problems if you explain it to them um...as best you can explain...um...cancer. I mean how do you explain it really? It's something that happens to you, but um...just this feeling you have...that you can accept it. And uh...your friends are much...they can handle it much easier than if you don't say anything.

Thus most families explained their ability to continue an involvement in the social world as a product of the strategies they had used in approaching other people.

In addition to their experiences in obtaining medical care, most families described having to receive help from outsiders as a result of having cancer. Many did not relish the idea that they were in need of any help.

FC: The neighbors have offered, but we really don't need them.
R: mm hmm.

FC: Except for company and uh...phone calls and things like that, you know. But other than that...other kind of help we don't need.

Thus one of the things families tended to appreciate was help that was subtle and covert.

FC: They seem very glad to see you and um...help without you being overly aware of their helping.

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FC: They like to help me too, you know, but always they just let me manage it and do...let me walk...something like that you know. I like to hold their hand in case I fall or something like that. So I said, "Let me walk," or if I can't walk and I need help I let them know. I get too independent (chuckle).

R: So they don't take over....

FC: Yeah.

R: ...and take away your independence?

FC: Yeah. That's right. It lets you feel better that way, Sally, if you are helpless.

Many families explained that the attitude of the helper was an essential factor in their ability to receive help without being distressed about it.

FC: None of them feel sorry for me, which is um...I always say one of the worst emotions one can have for another human being...is pity.

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FC: That's one thing I can't stand...pity from people.

Families explained the kinds of helping behaviors they appreciated from others in terms of the degree to which the help enhanced normalcy in their everyday lives. Several spoke of having meals brought to them by friends, and shared together, as the sort of simple and non-invasive help
they did not mind receiving. Many spoke of sharing information about cancer, hospitalization, and illness among friends as a helpful phenomenon. However, when this sharing also included hearing the gruesome cancer stories, several families, as mentioned previously, took evasive action.

Social interaction in general was perceived by these families to be helpful to them throughout the cancer experience.

MF: Oh gee, somebody's dropping in...the phone's ringing all the time.

R: It gets very busy around here.

FC: Yes. That helps...that helps a great deal.

R: That does make a difference?

FC: Oh yes. It keeps your mind off yourself and also keeps you busy.

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MC: The best part of it...I have fellows that uh...a lot of them came into hospital and visited me when I was in there, and they still keep in touch or phone.

Families valued friends who were able to maintain normalcy in their interactional style. For example, the woman in the following example enjoyed the fact that co-workers could joke about her hair loss.

FC: Like yesterday for example...uh...he was making reference and we...the economics situation being what it is...and he was making...he made some comment about...no wonder I've got grey hair. And I said, "Grey? It's white." And he said, "Well at least it's my own,"...you know. So this is sort of the rapport we have.

R: Yeah.

FC: And I said, "Well you always have the same hair style, which I don't." You know this is...sort of the type of banter.
For several families, listening was one of the most helpful acts that others could provide. Although the families tended to express the need to be heard as an occasional rather than a constant need, they were very clear about its significance.

R: Nurses are who you'd choose to talk to if you needed to talk to somebody outside the family?

MC: Yeah. Yeah.

R: Why nurses?

MC: Because I was around there...I think it was the second time I was there....

FF: The time they done the diverticulitis.

MC: Yeah. They done the diverticulitis...took out the spleen, abdominal lymph nodes, and done the biopsy of the liver all in one fell swipe. And I was feeling pretty dumpy one afternoon. One of the nurses came in to change the i.v. or some bloody thing and I started to talk to her and she sat there on the chair and held my hand. I guess I must have gone on for 20 minutes...just shooting my mouth off. I don't remember what I said. I was crying and everything else. But she just listened.

FF: Which is a big thing.

MC: Yeah. Just listened...just held my...I remember her holding my hand. I don't even remember who it was.

The families' decisions to accept or not accept the help of others appeared to be a form of strategy in normalizing their lives with cancer.

FC: There's all that help out there, and uh...and you make up your mind that you're going to accept it and respond to it in a positive manner.

Since most families did require help from outside sources, the strategies they utilized to minimize the impact of becoming a help recipient were to make decisions about the kinds of help they wanted to receive, and the context within which they were prepared to receive it.
A second type of strategy, which appeared to counterbalance the sense of being help recipients, was also described by all of the families. Each family stressed the importance of their giving help to other people. Several of the cancer patients and other family members continued regular volunteer or charity work in spite of the presence of cancer in their own lives. Others talked of the various ways in which they had been able to translate what they had learned through their own cancer experience into a means of helping others.

MC: I've helped more people since I got cancer in two years, believe it or not.

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FC: So anybody that talks to me now there...and I've had, you know, the odd one...they say, "Oh I think I have to have radiation. I'm petrified,"...you know. I'll say, "What for? There's nothing to it,"...you know. So...so you try to be helpful. And I talk to as many people as I can about it.

FC: Now to me that's uh...that's quite a plus, you know, being able to help people.

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FF: Well I think...myself...I'm very much aware of how people feel...when they're going through something like this. And I just hope that, you know, I've been able to help [name]. I hope I'm able to help others...or that both of us are, because we can honestly say, "I know what you're going through and have been through it." I think this is important, and sometimes as I say I think...well I guess the Lord has a reason for us to go through these if we can just understand. And perhaps what we in turn can do.

Thus the strategy of helping others fulfilled many purposes for these families. In addition to minimizing their sense of themselves as help recipients, it provided a specific source of meaning to the cancer experience with which they lived.
R: So there's something about the experience that gives you something that you can then use to help people that you perhaps didn't have before?

FF: Yes. That's right. I think...what would you say?...perhaps more sensitive to them? Rather than just giving out a sympathetic reply, maybe you're more sensitive to their real feelings.

As one woman described it, this extending of help to others explained her willingness to participate in this study.

R: So somehow having cancer gives you some specific and concrete uh...thing that you can offer to other people?

FC: That's right, and to help them.

R: mm hmm.

FC: And this in fact is why uh...we're um...you know...allowing you to take these sessions. If uh...certainly to help you with your thesis, but to hopefully to help other uh...cancer victims. And to me that's terribly important.

It appeared from the accounts of these families, then, that the constructive use of their own experience in helping other people was a meaningful strategy for maintaining a productive everyday life with cancer.

Although some of the families had friends or relatives with cancer prior to its diagnosis in their own family unit, a heightened awareness of cancer involvement was a feature of the social networks for all of these families. Several families claimed that those who also had personal involvement were much more at ease in discussing cancer than were those who had not.

MC: The people that are involved in this, we can talk about it quite freely.

R: The people who have some contact with cancer themselves?
MC: Yeah. Quite freely. But it seems to be uh...Now um [name] was 73, [another name], he's 72. They drop around here. No hesitation...you know...talk about it. Um...[another name], 88...84 and [another name]...they come in...and stuff like this...talked about it quite freely. It's the younger people...the sort of...(pause) Well if they've got somebody involved in it, yes, they'll talk about it. But they won't uh...maybe they don't know how to come along and say...well, like, I mean the guys in the shop say, "Jeeze, you're sure getting your color back...your hair's come back...you're sure looking great," and stuff like that. But it's the older ones. I'd say roughly 45 on.

R: mm hmm.

MC: Well maybe the younger people figure they're encroaching upon you. If they...like if you were talking to them and you brought it up, maybe they would say something.

R: mm hmm.

MC: But I mean you can't go around and talk about it all the bloody time. But anybody that is involved with somebody doesn't seem to have any problem talking about it.

They also found that acquaintances who had had cancer experiences sought them out more frequently than before.

FC: But uh...I've found since I have been diagnosed as cancer that she comes around far more often than she used to.

In spite of this apparent bond between those who shared similar experiences, none of the families in this study had participated, or intended to participate, in the cancer support groups available to them.

FC: Like I don't think it's going to be too helpful if we were to go to those um...meetings they have for cancer. You hear all about these other cases and...like uh...you could feel better after it I suppose, but uh...everybody's different like [doctor] says. Everyone's case is different.

Although none of the families believed that such overt attempts to compare their experience with that of others was appropriate or productive, they all engaged in repeated comparisons with cancer patients and families within their own social networks.
MC: And we were talking today 'cause I went to the doctor last week. She says, "How'd your tests turn out?" I says, "Nobody wants to see me for six months." She says, "God I wish I could reach that plateau." She lost her breast, nodes, and all that. She says, "The most I ever get is four months."

MF: I have had discussions with people I work with about their family member or friend who also has cancer and so far have not encountered an individual who has been subjected to what Mom was.

FC: [Son] tells me about his young friend, you know, and uh...I was talking to [another friend] about his father...how it went with him...how come he lasted such a short time.

R: mm hmm.

FC: But you do compare. You find yourself comparing.

The reported connections with other cancer patients extended far beyond individuals who were known to them personally.

MC: Then there's one of the editors...his brother...had much the same as I had...not quite to that extent...but he lost part of his stomach too from cancer, and stuff like this. Uh...and [name], his wife has one of the forms of leukemia that'll flare up and die down and flare up and die down. Sometimes she's quite sick for maybe three or four months. Then she comes out of it. [Another name], he lost his wife after five years of no reoccurrence. In six weeks she was dead.

R: Sounds like you both knew or know of an awful lot of people who've been involved with cancer. Do you find that you know more now that you're involved with it yourselves?

FF: Well it seems to come up more now. You hear of it more.

The experience described by these families was not one of isolation. Their involvement with cancer seemed to open them up to a new, and perhaps symbolic, sense of community with fellow travellers in the cancer experience.
MC: When somebody tells you you have cancer, you think you're the only person in the world that has it. Then you go out to places like that [clinics] and you realize there are thousands have it...in all different kinds and shapes and sizes.

FC: I just used to hear through [husband]. I didn't...I knew her from seeing her at Christmas parties but that's all.

R: mm hmm.

FC: We weren't close friends or anything. But we have...like the lady that was here has had a cancer scare.

R: mm hmm.

FC: And then we have another friend who's had a breast off....

MC: One's surrounded. I spoke to a lot of them. "I have cancer, I have cancer." Right here in this building.

MC: But we know of the same thing happened to a family....

Although the cancer stories, as discussed earlier, produced considerable distress at times, they also served as a means of reinforcing this larger sense of community.

The emergence of a new social network within which to experience everyday life was a phenomenon shared by these families. The strategies they applied to the evolution of a supportive network included using tactics to maintain friendships, finding ways to receive help, extending help to other people, and making connections within the real and symbolic community of cancer patients and families.
Managing medical care

The third major theme in the families' explanation of the impact of cancer upon their everyday life related to the management of medical care. Although medical aspects of the experience were not an intended focus of this study, the theme emerged as a significant factor in the ways in which families explained and understood their experience. It was apparent that concerns arising from the medical management of the disease held the potential for significant impact upon the families' day-to-day lives.

Frequent mention was made of the impact of treatment processes, hospitalizations, and health care personnel on the experience of living with cancer. It was, however, the impact of the doctor that was described by all families as being the most influential factor.

FF: I think that's another part of this. If your doctor is good you trust him.

There was a need to identify one physician as the authority figure in the medical management of their illness.

FC: I think you've got to follow one doctor. You could go crazy trying to follow everybody's ideas and...

R: mm hmm

FC: Especially when they contradict each other. You could make yourself a lot more sick, you know, by following all these ideas

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FC: What can you do? Like you could change [doctors] and keep changing and make a big mess of it yourself.

The power of the doctor over the lives of these families was explained by their beliefs that his values controlled the amount of information they would receive, and that his interest in their case determined the effort he would expend on their behalf.
The first strategy used by most of these families to deal with this new authority in their lives was to develop a set of criteria upon which to evaluate doctors. Doctors who took the initiative in offering explanations were valued by these families.

FF: They'd talk, and tell me what was what, and why they were doing such. And I think that's wonderful for people because so many people are frightened. They're afraid to ask.

The explanations were further valued if they were perceived to be honest and understandable.

FC: What I liked about him...he didn't hum and haw like some doctors uh...they shake their head, they cluck their tongue, this kind of stuff. You think "Oh my God". But, you know, he was right to the point. And I like that kind.

FF: They don't seem to realize that the patient and the family need to know what's really happening. If the doctor explains that what he is about to say is only his educated opinion, not totally substantiated by cold, hard facts, and it turns out wrong later, it doesn't matter. He's not going to be sued for being wrong but he'll be respected for being honest and, more importantly, he'll be trusted by the patient and the family.

Where families had difficulty acquiring the information they desired, they experienced considerable distress, as evidenced by this excerpt from one of the letters to the researcher:

MF: She asked the specialist to draw her a picture of the areas engulfed in cancer and how that affected her back. He picked up a scrap piece of paper from the table and drew a picture. Mom asked if she could keep the picture. The specialist said no as he had written on one of her records. Crap! - that was a scrap piece of paper! Through this whole charade it appeared the specialist was so worried about his rear end he would not give a straight answer. Any question which was asked was given a general answer which could have applied to half the population with cancer. It is incredible to my way of thinking that the medical professionals can operate in such a manner.
In such instances, their evaluation of the situation lead to the conclusion that the doctors lacked essential skills.

FC: Well I think you're very much aware that certain doctors are not good communicators.

R: mm hmm

FC: They um...certain of them, they're very knowledgeable in their field, but uh...they...I don't know if it's they assume, or they just...it's the type of personality...but they're not prepared. They figure "Well I told you this. This is the way it'll be and no questions asked."

For many families, this degree of interest was inter-related with information giving.

R: So a lot about helping people get healthy isn't just having the technical competence to deal with whatever chemical process is going on, but it also has to do with helping the patient have information and attitudes that are going to help them get better as well?
FF: Well this is it!

FC: Well you know the fear of the unknown...as they refer to, and uh...I know from my discussions with [doctors] that there's no cure for uh...breast cancer as yet, but uh...there are many things they have to treat it. And uh...I mean...so I mean that gives me confidence in him that he's not going to give up too quickly, and uh...therefore, I certainly am not.

Since most families perceived that they did not have the expertise to evaluate doctors on the technical aspects of their competence, they tended to assume doctors were equally competent, and that this competence would be applied to their case if the doctor was interested. This interest was measured in terms of the attention that doctor paid to social interaction with the families.

FC: He has been really...you know...really good...at visiting in the hospital and...he was really good at [name of hospital]. He was there everyday to see me.

MF: Where the lady in the next bed, her doctor didn't come in at all.

FC: Yeah. He hardly ever came to visit her...and uh...you know...it was good to see [my doctor] there...

R: mm hmm

FC: Everyday and that...and interested in how you were doing.

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MC: And I'd say between [all the members of the oncology team], they were concerned about me. It wasn't just...'cause during my times in hospital, I saw a lot of nonchalant doctors attitudes. And some of the nurses too.

It was also measured in terms of empathy and accessibility.

FF: [Doctor] came out and he was very nice to me. He was the most consulting doctor there is.

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MC: There is the big thing...that [my doctor's] accessible. He said "I don't want to see you for six months, but if you think you've got a problem, phone me."

R: mm hmm

MC: This is the big thing. Not Goodbye. Get-the-hell-out-of-here attitude.

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FF: But then [our Doctor] has a consoling...he's a doctor...he's uh...it can go on the tape and he can listen to that...that he's...he's got personality.

R: mm hmm

FF: He's understanding...and if anybody gives him a rough time, there's something wrong with them, because he's a doctor that anybody could have. He seems to be a doctor that has a feeling for people.

Absence of these skills seemed to invalidate any competence a doctor might have.

FF: Now there's one doctor is [named doctor]. He wouldn't be too good for me or any other patient because he's too in a huffy. And there's another...there's another doctor...I'm not calling all doctors...but there's a doctor I had...he was jumpy.

R: mm hmm

FF: And you can't have a jumpy doctor. You know what I mean?

The significance of the doctor's communication and his interest in the family's everyday life was reflected in the following two examples:

FC: I think it's [my doctor's] attitude that takes away any hope that we could have. Like uh...he seems to be one that does give you all the black side...or you know, like he just won't give you any hope. He, just seems to um...if you do try to get some hope through him, he just thrashes it all down.

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FC: I wonder, though, if he has bothered really to look at these charts. He's a very busy person and I wonder if he's bothered to look at my reports.
Thus it was the experience of these families that confidence in one doctor was essential, and that this confidence depended upon the degree to which the doctor seemed interested in their case and was willing to provide the information they required. Where interest and information were not generated by the doctors themselves, families evolved a number of strategic approaches toward rectifying the situation.

All families spoke of their desire for information, although the nature and extent of that desire varied considerably.

MC: I'm a very curious person
R: mm hmm
MC: I want to know...this is my body.
R: mm hmm
MC: I want to know what's happening to it. If I have a malfunction, well then the malfunction should let me know what's wrong with me...

Some families described assertiveness as a strategic approach to obtaining information.

MC: They would happen to meet him in the hall on the way down to see me or something like this and "how's things going today with my father" and stuff like this. And if he told them some things that they didn't think jived when they saw me...back down the hall they'd go.

MC: It's the old thing that the squeaky wheel gets the grease.
R: That's what you felt?
MC: Yeah. And if you don't put up a bit of a bitch, you don't get nothing...in lots of cases.

Searching out alternative sources of the doctor's privileged information was also mentioned.

MC: I don't say I've got a great amount of knowledge, but I sort of have an idea what to ask and what to look for. And if I don't get an answer from one, I get it from another. And I mean, you would sort of cotton on to one nurse who was more appreciable to you and would answer your questions and other ones would sort of snuff you off. You can sense this. And uh...same as a lot of residents. The same way.

Several families reported that they had taken the initiative to direct the doctor toward the type of information they required.

MC: Well that's one thing I appreciate about [my doctor] is that he's very straightforward. Well I said to him "Hey, I don't want you to hide anything from me. I want you to tell me exactly as it is. And I want to know" I says "'cause I'm not scared about it. I'm not, you know...I'm not upset." And so he's been very straightforward with me. I feel anyway. I really do.

One family perceived aggressive action to be appropriate when a doctor was not perceived to be concerned enough about their care.

FF: Some have interest. Some haven't got interest. Some have to be abused.

Beyond these approaches, a strategy common to all families in this study emerged as they described their efforts to humanize the doctor. Where the doctor was not perceived as fulfilling his role effectively, many families attempted to understand the doctor as a fellow human being.

FC: I think in his own way the...the night he came to visit me in the hospital at midnight...I think he was trying to tell me in his own way that I was...he kept repeating that I am a very sick woman...

R: mm hmm

FC: ...and I don't seem to realize it. And I said "Well I do realize it. What do you mean I don't realize it? I know I am." And uh...but maybe in his own way he was trying to tell
me to go out of the hospital now while you get the chance.

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FF: Doctors get cancer...quite a few of them.
MC: Well, they're around cancer patients. I don't wonder. They're not exempt no more'n we are. People that looks after it are no more exempt than we are.
FF: Well there must be quite a few up in Penticton then, because [named doctor] got it. And there's another doctor in Naramata. I didn't know him.
MC: I've know doctors that passed away with sugar diabetes, with cancer also, and with heart troubles. Oh yes, they have the same troubles as everybody else.

When perceived as ordinary mortals, doctors were permitted to be fallible.

MC: And my first question was "If I don't take any treatment for my cancer, how long will I live?"
R: mm hmm
MC: Now I think he gave me a lot of B.S. (chuckle). He told me two months. And the other doctors told me a year.
R: What do you make of that?
MC: I think he's just trying to frighten me.

Accepting the doctor as a fallible being did not erode any confidence they felt in his ability. Rather, it helped families regain some sense of control over their own medical management.

MC: But here's what I figured out too. Now no matter how good a nurse is, no matter how good a doctor is, no matter how good a hospital is...if you don't help the doctor and your nurses and your surrounding, you can't...they can't help you. Nobody can help a wall, 'cause it has no sound. You know what I mean?

Humanizing the doctor also included recognizing that doctors were subject to personal insecurities. In light of this, several families mentioned strategies to enhance the relationship by comforting the doctor.

MC: It takes a little while to get to know him (chuckle). But some people just don't like him...you know...for that
reason...his personality. But I can get along with most everybody. You know I kid him and we get along real good.

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MC: I said "O.K., come on. Where to go from here?" He looked at me and he says "Well...I heard you're pretty forthright." I says "that's right. I want you to be forthright with me. I mean how bad is it?" He says "Well" he says, "the type of lymphoma you've got" he says "is deadly serious." I said "Fine. We'll take it from there." He sat back. He says "Well thank you." And that's the way we've played it. I mean I haven't tried to con him, he hasn't tried to con me.

The strategy of extending themselves toward health care providers was employed by most of the families who participated in this study.

R: You were saying earlier that you thought perhaps your attitude when you went...when you approached these medical people had something to do with how well you were treated.

FC: I think so. I think so.

R: How does that work?

FC: Well, you know...I think you go...if you go in with the uh...sort of friendly attitude and...you know all...not "poor old me," and you're sort of feeling sorry for yourself and that...um...you see those kind of people. And I notice that when some professionals are working with them, you know, they sort of do the thing and that's it. But uh...I've found if you're friendly and you're...ask them how they are. What the heck, eh? They're human. They have...you know...problems...medical problems and...and various other kinds. Don't get it...you know it's all inward. It's not "me, me, me," it's...you know. And I think people respond to that.

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MC: At the same time, although I was sick, there was a lot of people that were a lot sicker and needed more care. So I gave them my...the time that they would spend with me to deal with people that really were sick.

R: mm hmm

MC: And yet sometimes I was really sick. I didn't let them know. So you see you can compromise with people that's concerned. Very much so. Yes, there is such a thing as meeting them on equal footing...realizing and understanding that they have
their job to do, and do not waste their time because their time is precious.

R: So if you treat the nurses and doctors that way...

MC: In turn you get your reward just the same. They do as much for you in turn, unknowing to you that they did it already and are doing it.

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FC: I had to go over to the cancer clinic. Uh...these ambulance drivers and that, they were the most marvelous helpful people, and this has been...uh...a great strength. When you show that you want to be helped then...and your attitude is such...uh...I have not in all this time met up with one person...technical, medical, whatever...that hasn't been overly helpful. And I just can't say enough about these people.

Thus families cared for the health care providers as a means of facilitating the kinds of care they in turn hoped to receive.

In general, the families stressed that the perceived quality of medical management had significant impact upon their everyday lives. Much of this perceived quality was represented in the personal style of the doctor they viewed as in charge of their care. They evaluated their doctor largely in terms of the information he shared and his expressed interest in their case. Where doctors failed to measure up to these criteria, strategic approaches were employed: a variety of assertive overtures were made in the effort to acquire information; the actions of doctors and other health care personnel were explained in the context of human inadequacies; and finally, understanding and support were extended to the health care providers. These strategies facilitated valued behaviors in those individuals whom the families had entrusted with their medical management.
Generating hope

The final theme in the families' accounts of strategic approaches that explained cancer's impact upon their lives was that of generating an understanding of the illness, which offered a measure of hope. Two general strategic approaches will be discussed in this context: demystifying cancer and finding something to have faith in.

Demystifying cancer was a general strategy that included a variety of ways to minimize the fear experienced by families. Fear was strongly associated, according to these families, with the worry and self-pity discussed earlier in this chapter. Families viewed fear as the antithesis to hope, thus conquering fear was an important goal for all participants.

Families in this study were well aware of the fear associated with the word "cancer" in their society.

FC: It's been a fearful word, you know, the name 'cancer', you know. Everybody...as a matter of fact there are many they won't even voice the word, you know.

FC: What I have found, all the way...firstly, people are terrified of the word. It's just...they talk...they get around...everything but use the word.

FC: People are reluctant to even use the word. It's uh...just strikes fear into the hearts of so many people. And as I say, it's a lot of ignorance.

Most of the families claimed that using the word "cancer," and encouraging its use among their friends was a useful fear-reducing tactic.

R: So you've used that word..."cancer" in describing it?

FC: Oh yeah. Sure.
FF: Oh we don't flinch from it...when you think, by God, it's just another word.

FC: That's right.

It appears that calling the "enemy" by name was a valuable demystifying strategy.

A second strategy employed for this purpose was that of acquiring information from alternative and non-traditional sources. Hypervigilance to potential information sources was evident in all of the families. Use of contacts with other cancer patients and the use of cancer stories have already been discussed in this context. As well, most families used the opportunity of the research interview to ask this writer for her ideas and opinions about cancer and its treatments. These requests required the researcher to refer families to appropriate members of their health care team, and such referrals were generally received with enthusiasm at discovering an additional information source.

Books and articles were also mentioned as frequent sources of valuable information.

FF: Now chemo we know about because we read the book.

R: mm hmm

FF: And we have the book here. But in the other [i.e., radiation] we don't know a thing about it...yet.

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FF: See all these uh...Chatelaine magazines here?

R: mm hmm

FF: Why I keep them is because it's got...um...medical in it.
Several families acquired information about cancer from television programs.

FF: But uh...I think that uh...that people are getting and learning more all the time...and reading more. And if people are at home watching their T.V...which a lot do...there's a lot of doctors and...and scientists come on the air. And there's a lot of good conversations go on.

R: mm hmm

FF: And I think, myself, if you...if you are a T.V...I'm not...not in the daytime...but uh...you can get a lot of help there.

These alternative information sources helped to demystify cancer by considering it in contexts external to the exclusive realm of medicine.

FF: He's a great reader of things.

MC: Oh yeah.

FF: He wants to know everything about everything. 'Course I'm the same way. I never take a pill or liquid without knowing what the contents are.

MC: I'm trying to cure myself with garlic.

R: It sounds like you're prepared to try other kinds of remedies to ease up your symptoms than things the doctor gives you.

MC: Oh my. I'm going to try anything. See...listen. I'll show you some other article that I've got...where a fellow from North Vancouver went to Arizona and he got cured.

Thus, although the information acquired from alternative sources served a number of purposes, it generally helped families understand cancer in a context that was relevant to their current needs and over which they held some control.
In some families, information was used to construct an explanation for why they had succumbed to cancer while others had not. It appeared that in the process of answering "Why me?", several families had adopted an answer that was factually unsound but which suited their purposes.

MC: What actually happened was when I come down on that corner one day, I went to my stand and here's a great big gob of phlegm somebody spit up. It probably was cancer phlegm. You can see when I come to think of it now...and the germs from there...plus other germs, you see, naturally I contacted it. Obvious to see (chuckle).

R: So you think there's lots of possible ways you...

MC: Yes there is. Because you think now...a person, if he's got lung cancer, and he's smoking...that smoke goes in the air. You're inhaling that air. I don't care who we are. We're talking taking that air in...unless there's purification or disinfectant in the air at the same time. You're bound to get a certain percentage of it. And it may not hurt you for years.

R: mm hmm

MC: But then as soon as your system starts to run down, then it'll take hold of you.

Although all families were aware that current medical opinion refutes germ theory about cancer, several chose to consider contagion as a possibility. The value of such a strategy lay in its ability to demystify the cancer.

The hearing of negative cancer stories has been described as having an impact on families' understanding and fear of the disease. In an effort of demystify the disease, some families developed strategies with which to reinterpret or invalidate the stories.

FC: And you don't hear the positive things about it. And uh...that has been more or less my experience.

FC: You know how things improve so greatly in the telling.
Others selectively attended to only those stories that would help them generate hope.

FC: Well I have hope that...like you hear about these other cases where they get uh...five years, but you've got to think about that. [My doctor] never gives me any hope.

A final approach to demystifying cancer was that of placing it within the context of other phenomena which were more easily understood. In the course of constructing their accounts, these families variously compared selected aspects of cancer to such ailments as arthritis, amputations, allergies, and ulcers. Putting cancer within the context of other processes served to reduce its ability to produce fear.

FF: Well I think we mentioned this before when you were here. When I was young, pneumonia was a dreadful disease. And before that it was smallpox. That was years before me again.

R: mm hmm

FF: And all these things, they...there's a terrible fear built up in people, and then uh...now at this moment, it's heart and cancer.

The end result is...could be fatal, but then that doesn't matter what you have. Even, if it's uh...just through old age. You will expire.

These comparisons were invariably used to demonstrate the positive aspects of having cancer.

FC: Well, if I had my druthers, I druther have what I have than say...a heart condition.

The strategies used to demystify cancer and reduce fear, then, included: using the word, acquiring outside information, developing beliefs about cancer, reinterpreting cancer stories, and comparing cancer to other phenomena. Most families described their strategic approaches as
highly successful and believed that, as a result of having to face cancer, they had conquered a fear common to most of society.

FC: I think the fact that one is a victim of it or one is a relative of a victim of it...um...there is less fear, because as I say, it's back to the same thing, it's uh...knowledge. You know more about it. Before, you didn't know a thing. You were afraid to even bring it up.

By reducing their fear, families perceived themselves to have prepared the way for acquiring a sense of hope.

The families employed a number of strategies toward finding something in which to place their faith. The term 'faith', generated by the families themselves, rarely implied faith in the religious sense. Rather, it signified reality-based beliefs upon which they could place a measure of hope. All of the families spoke of facing reality and acceptance as essential requirements for building this faith.

MC: You've gotta face up to the facts, and there's no point in trying to...pardon me...bullshit your way through. You've gotta face up to the facts and...O.K., through all our lives we've gotta make decisions, we've gotta make plans, and sometimes you blow them. But don't turn round and go and get smashed out of your mind or put a gun to your bloody head. That's no solution. Face the fact that you just pick up the bits and pieces.

Acceptance had to do with acknowledging cancer as a part of living.

R: But you're saying that there's a...kind of an overriding feeling of acceptance, of calm...that kind of overrides those other ups and downs?

MC: Oh yeah. Oh for sure. For sure.
FF: And you can't really explain it either.

MC: No. It's just something that you have, and accept it, and, you know, you live with it. It's one of those things.

FC: At least our family's all grown and...you know...thank God for that. They've all gone...on their own and the baby's 25 or he's...they've made it, eh?

MF: It's something...another phase of life.

R: mm hmm

MF: A part of living.

For several families, acceptance also had to do with acknowledging the inevitability of death.

FC: The good Lord is going to let you stay as long as...it's His decision isn't it.

MC: As I say, I face every day not as "Oh this is the last...one of my last days" type of thing. I face it with "If the Lord's gonna keep me here - fine. If He wants to take me home, then that's gonna happen. Um...I don't want to be flippant about it or anything. I just feel that way, and that's the trust I have. And uh...I think it's so important that you have something like this to grasp onto, 'cause human-wise, what can you do? You've got the cancer, and it's there, and it's going to happen to you. The Lord uh...can heal you in a very mighty wonderful way, and if it's His will to be healed then I'll be healed.

MC: So my time comes...well glory! You know what? Death is the greatest challenge to any person living. That's the greatest challenge in the whole world, no matter what you've done, because our time span is the snap of a finger. That's all it is. So the greatest challenge is what's beyond death. We're not going to float in this uh...cosmic uh...area of ours for ten trillion years before Judgement Day. And I'm curious about that. So when my time comes, I'm going to die with a smile on my face. I really am.
Facing and accepting reality, however, were only the beginning points from which to build faith and feel hope. All families perceived acceptance as negative or defeatist if it did not also include the desire to "fight."

MC: Life is...from the time you were born from...you leave the womb 'till the time you hit the grave which is your destination, you got your destiny which we all go through...is nothing but a struggle. That's all it's been from the fetus on and it's not going to be different now. No matter who we are. We gotta learn to accept facts and life as it is given to us and as it goes...as we live through it. If we don't, we don't make this world very long. And that goes for 95 percent of the population of this earth, not for one or two.

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MC: That's the big crux of it...you're not gonna be beat down. You're gonna fight and fight and fight and fight. Whether you fight physically or you fight mentally...or jointly together.

Many families articulated the belief that a fighting strategy did have the potential to postpone death.

R: So you had two friends, then, that died of cancer before you got it?

MC: That's right. Because they would not fight for their own... until it got too late.

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MC: If they fight for themselves, it might be a great hope. But if they don't fight for themselves, there's no hope. There's nobody...nobody's genius and can put life into something that's already going.

Several also suggested that if fighting did not postpone death, it would still improve the quality of the life that remained.

MC: I said to [my doctor] the other day "You're going to have me for a patient for a long, long time" I said "I'm not giving up voluntarily. Don't kid yourself."

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FC: They say that it can be beaten and uh...I guess I'm stubborn enough and strong-willed enough...
R: (chuckle)

FC: I figured if it's going to get me, I'll tell you it's gonna... I'm gonna put up an awfully strong fight.

R: And you're going to enjoy yourself in the process, it looks like.

FC: And you'd better believe it.

Thus acceptance, combined with the will to fight, were perceived as essential elements in the families' generation of hope through faith in their own abilities to confront and impact upon cancer.

All families also expressed the need to have faith in something other than themselves and their own capacities to fight the cancer. Most admitted to a faith that medical science would find a cure for cancer in the near future.

FF: You know, every year they come up with something a little better.

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FF: I have great faith that they'll come up with uh...a new drug. They'll get it one of these days...very shortly.

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MF: And I personally think that on the basis of what they've done in the last 20 years in the medical field...I strongly feel that...that the time's not very far off that they're gonna come up with a cure.

Many supported this faith by following the progress of cancer research in the news media.

FC: Thank God people are responding and uh...they don't lack funds for research...that's for sure. They don't know what to do with all the money. But there fortunately is an area where they are making great strides.

R: mm hmm
And that Terry Fox... that money they raised there was unbelievable. And there are millions still in the bank account, you know. Just the interest it's leaving. And uh... they've turned over a million here, a million there to some of these researchers. And I'm quite sure, in another five, ten years...

Well you know you read... I read anything I see if it's something concerning my particular area and...

I listen a lot on the air if I'm home... for the different... 'cause they've always got somebody of interest on medically and they come up with new stuff that they're trying.

All families also expressed the need to have faith in their doctor. As has been discussed previously, doctors were not necessarily perceived to be worthy of the family's trust. However, in spite of their evaluations of doctors as imperfect, and in spite of their beliefs that doctors needed coaxing to provide the best cure possible, the families unanimously reported their decision to place faith in the doctor.

But as I say, you've got to have faith in somebody, and up 'till now [doctor] has played pretty square with me.

You gotta have faith in people that is trying to help you.

mm hmm. Like the doctors?

Like the doctors.

Nurses?

Nurses. And certain amount of the medications.

You've got to listen to somebody, so it might as well be your doctor. You got to have faith in somebody.

Thus no matter how critical or manipulative they were in regard to their medical management, the need to place their faith in it remained.
The acquisition of faith was described as having considerable consequences in shaping the family cancer experience.

MC: There's no question in my mind about that at all. Without faith, I don't know how you would face problems like this...because it is a problem...there's no doubt about it...but you have to have something you can, you know, rely on...something to hang on to.

With faith, whether it be in themselves, in medical science, or in their doctors, families were able to generate the feeling of hope.

FF: Where there's that little bit of hope...where there's that 20 or 30 percent chance that the chemotherapy will work, then that's all I've got to cling to and that's what I hold on to. 'Cause that chance is there.

FC: At least you...you know...you could hope for an extra year or...you know

R: So what you're saying is, there's always something to hope for.

FC: Yeah. Why not?

Therefore, the strategies used by families to acquire faith included: facing and accepting reality, fighting back, and placing their faith in medical science in general, and their doctor in particular. They clearly expressed their need to have faith in something and described how their faith promoted hope. The fact that most families were able to feel hopeful most of the time was evidence of the success of their strategic approaches to demystifying cancer and finding something to have faith in.

Thus, in explaining the cancer experience, families described elaborate strategic approaches toward minimizing the impact of cancer upon their everyday lives. Although all families perceived their own approach to be the most successful choice, many of the approaches they described
differed radically. Since various strategic approaches produced the same desired outcome (i.e., the perception of living a normal life in spite of cancer), that outcome was not simply a function of correct or incorrect choices. Rather, the participants explained, it had to do with the fit between the strategic choices they made and who they were as families.

**Integrating the Experience into a Life Context**

The two previous sections of this chapter described the family cancer experience in terms of cancer's impact upon everyday life, and explained the extent of that impact in terms of strategies and choices employed by the families in coping with the presence of cancer. The accounts illustrated similarities and differences between families, and also contrasting perceptions within families. This final section of the families' accounts penetrates the third layer of that explanation of their cancer experience. It integrates the parts described previously in this chapter, and thus explains how families make sense of the complexities and contradictions inherent in their cancer experiences.

Throughout their descriptions of the impact cancer had on their lives and their explanations of the strategies they had chosen in order to moderate the impact, families repeatedly referred to the significance of attitude. All of the families participating in this study believed that their attitude had been an important factor in shaping their experience with cancer.

**FC:** As I said to you much earlier...we're gonna give it a good fight. And...and that's why...and I keep using the word attitude.

**R:** Yes?
FC: And I...I believe that's the key.

MC: There's nobody can change it once you have it. You have it...you have to overcome it by your attitude.

R: So you think your attitudes about it's had a lot to do...

MC: Attitude of mind. Yes it has very very much to do with it.

According to the families, the attitude with which one approached the cancer experience affected all facets of that experience.

R: Well do you think this positive attitude has anything to do with facing reality?

MC: Yes it has. Because if you think positive, you're gonna live positive.

R: mm hmm

MC: Think positive, live positive, work positive. If you're gonna think negative, you're gonna be negative within yourself. So you see, it has a...a very, very big factor of how far the positive thinking goes. It's more beyond than we can really realize. It's a big...it's a small word with a few letters, but has an awful lot of power.

R: It's a powerful part of what it's all about.

MC: It's a powerful part of...part of what our actual build up of life is. It very well is. That's bar none and fool none... even in the universities.

Their cancer experience, they claimed, was more a function of their mental attitude than it was a function of the actual disease process.

R: So it has something to do with mind over matter...or state of mind as you say?

FC: I think so. Very much so.

R: mm hmm

FC: Uh...as a matter of fact I'm a firm believer in it.
Most of the families used the terms "positive" and "negative" to describe attitudes that would enhance or harm families in the process of living with cancer. These families all perceived their own attitudes to be positive.

MC: A positive attitude is certainly the best attitude a man should have during the whole...by doing that, they help themselves.

Positive attitudes were perceived by several families to have a direct impact upon the actual progress of the disease.

MC: And uh...if a person thinks positively, there's less chances of continuing cancer. It could be dormant.

These attitudes also facilitated a sense of responsibility and control over the experience.

FC: You say "Well what can I do?" now you know..."what is my defence to this."

Several families talked of the significance of positive attitudes in moderating the emotional impact of cancer.

FF: Maybe that's one of the things...when I look back over the last five years uh...I think it's always...we've always sort of said "Well at least it isn't so and so...at least, you know, at least you're feeling...you aren't sick with it." I think we keep looking at the positive part of it and not the negative.
Positive attitudes were also perceived to be important in facilitating a high quality support network.

FC: I feel um...the doctors, the nurses, the radiologists...everybody I've dealt with...because of going in with them and with the right attitude, they respond in kind and are very supportive. And um...people I work with, perhaps because of this same attitude are supportive. Uh...my family are supportive of it. So that's what I mean by saying having the right attitude.

In addition, positive attitudes were described as facilitating high quality health care.

R: How do you think this positive attitude makes a difference?

MC: The positive attitude makes this much difference that it gives your doctor more faith in your treatment, it gives you more understanding of what it's all about, it gives you better strength to...to fight it, and make the best of what's left...and if you go, you go.

R: So the positive attitude results somehow in health care people knowing you, and getting to know you better?

FC: Exactly. Exactly. And uh...they take more interest in you, and you walk in and they know you by name and uh...they can tell from treatment to treatment if you appear any better or look any different. And um...which to me is very important. I feel uh...there again, we're talking about numbers versus uh...being an individual. And I think um...they in fact do treat you...or I feel they treat me definitely as an individual.

R: Yeah. And that comes from...partly at least from your attitude?

FC: I feel...yes, in fact.

R: Now this attitude's something that came from earlier experiences in your life. Is that an attitude toward life rather than an attitude about cancer?

FC: Oh indeed. Toward life.
Thus most of the families explained that their perceptions about the cancer experience and the strategies they had used stemmed from the positive attitude they held. Although the positive attitudes articulated by families all served a similar purpose, the nature of these attitudes varied from family to family. In fact, what one family described as indicative of a negative attitude might be perceived by another family as positive. For example, while some families perceived planning for their future to be consistent with a positive attitude toward cancer, others argued that their positive attitude directed their choice not to plan ahead. Families' choices to express or not to express emotions, and to discuss or not discuss cancer, similarly arose from what they described as their positive attitudes. Thus, each family described their unique interpretation of what a positive attitude toward the cancer experience entailed. One patient explained that while some aspects of positive attitudes could be shared, others would always be different for each individual.

MC: Not two person's mind think the same. There is not two person's mind think the same.

R: So the positive thinking is something that's different for each person?

MC: That's right.

Thus the attitudes held by each family toward their cancer experience explained how they had interpreted it and approached it. Understanding each family's approach demanded understanding of its attitudes. As families clearly and emphatically explained, their attitudes toward the cancer experience had something to do with their attitudes toward life in general.
MC: That's where your...that's where your positive thinking comes in. It's not a...it's not something that's uh...I made up. It's not something that uh...anybody makes up, you know. But if you do hear that more...from other families...yeah, positive thinking is a...is a dead factor.

R: mm hmm

MC: That's our...most of our bearing in life is on positive thinking.

It was evident from the accounts of these families that attitudes toward the cancer experience were constructed long before it was actually encountered.

FF: I think that it's peoples attitudes toward themselves have a lot to do with it.

R: Their attitudes toward themselves in general, or in anything specific?

FF: In general. General.

R: So how you cope with it as an individual or family has something to do with how you've lived your life and how you feel about yourself?

FF: Right.

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R: So that's something you learned long ago. And when cancer came you thought "well I'm going to apply that same lesson here?"

MC: That's right. That's right. I never quit thinking that way.

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FC: I guess I've gone through life. That's my attitude towards life...um...to be independent...strong-willed...perhaps stubborn you can say. But uh...you sort of set goals and you uh...you go out of your way in certain areas to achieve these goals. And uh...I think I'm using this same sort of attitude towards the cancer.
Thus, they agreed, understanding their attitudes required an understanding of who they were as families and how they had lived their lives. One participant termed this the family's "life concept." According to him, this life concept had to do with the beliefs families held about themselves and the philosophies with which they characteristically approached the issues that arose in the course of living. Although the term "life concept" was not used by other families, they all gave clues as to what their life concept might include. The following excerpts serve as examples of how families explained who they were and how they lived.

MC: In this world you gotta be a fighter for everything...for life, for necessities, for health. It's a fighting world.

MC: Don't let nothing beat you. I mean don't stick your head in the noose, you know, or be stupid and take a chance, but, I mean, you come up against your challenges...you step back a little bit and say, you know uh..."this is not going to beat me. There's no way."

MC: Never think you're better than somebody else and never let somebody else think they're better than you. We're all equal if we want to equalize it out. And that's what you call positive thinking.

R: So even the little ones can look on the bright side. That family philosophy seems to go right through.

MC: Well that's the way we've always looked at life and I guess it's uh...we've rubbed it...it's rubbed off on the kids.

MC: We're a bit of diggers.

R: You're diggers?
MC: We don't take...uh...I mean uh...you could give us an answer, and if we don't like that answer, you know, we're going to fish around for something uh...a little bit deeper or more clarity.

As each family explained its approach to life, individual members attributed the origins of the approach to early experiences they had encountered. Wartime experiences were frequently mentioned.

R: So you had to learn that in order to...to survive the war, and then you didn't lose that after the war was over.

MC: Well...that's how you become...that's how you get survival...positive thinking.

I mean I came to Vancouver in 1945 out of the Navy. I had 50¢ in my pocket. I knew nobody in town...no bloody thing. And I just started off from there.

R: So it's the same attitude that got you successful then that's keeping you successful now?

MC: That's right.

Early childhood experiences were also described by many individuals in the process of accounting for who they had become.

FC: I was three when my father left...and uh...the dirty thirties etcetera. And mother did everything to keep us going.

R: mm hmm

FC: And we learned, you know. And we learned that with a...

FF: And she made sure of it too.

FC: One of the greatest learning experiences we ever had, you know. And there were things that certainly have held us in good stead throughout the latter years when we've had some of these adverse conditions.

I was raised by my grandfather. I wasn't raised by my own
family. I had to learn to live with people, learn to understand strange things...

The impact of having lived through the Depression years was an explanation common to many participants.

MC: See...we were Depression kids.

Thus individuals easily accounted for who they were and the ways they had chosen to live their lives.

Although the origins of the beliefs and philosophies were described by individuals, families were also able to describe the process by which they had evolved a family outlook on life. In some families, members described themselves as harmonious opposites in the way they approached life. In other families, the beliefs and philosophies had become more and more unified through the passage of time together as a family.

R: So that sounds like your overriding philosophy that no matter what things happen in life, you face it and you keep hopeful and positive and things will work out.

MF: Absolutely.

R: [to FC] Did you start out with that philosophy too? Or is that something that's grown between the two of you over the years?

FC: I guess I have always thought along that same...more so since I met [my husband] though. Far more so.

The relationship between who they were and their ability to successfully live with cancer was an essential element in the account of each family in this study. According to these families, people who cannot cope with cancer are those who cannot cope with life.

MC: Well I think it's something you're born with, you know. It's the same as a hyper person and a non-hyper person. I think you just born with it...

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FF: Oh it must be something you learn along the way, 'cause we... you're looking at two entirely different personalities here. And yet...maybe it's something that you grow with. Could that be it? Something that you develop and that you grow with? It's an attitude right from...I don't know. I really never thought of it.

MC: It's...it's within a person's breeding in fact. It's uh... fate has a lot to do with it. Surroundings has a lot to do with it.

Since they perceived that attitudes conducive to living successfully with cancer were the outcomes of heredity and/or a lengthy learning process, these families were doubtful that people who had not developed positive attitudes toward life could acquire such attitudes when confronted with cancer.

FF: You can't teach them unless they want to learn.

R: So you're a believer that people learn things, and people learn attitudes.

MC: They either learn the wrong way, and get hurt, or they can start thinking the right way and keep...keep going.

R: If you haven't had that attitude up until the time you have cancer, do you believe that a person could learn that attitude?

FF: With difficulty, if you've not had the type of uh...mental attitude my [relatives] had, you know...the positive outlook on it.

Thus, the families explained that in the final analysis, they were the same people they had been before cancer had entered their lives. Although cancer had presented a challenge greater than most had ever confronted, they approached the experience with the same attitudes they
had applied to all other challenges in their lives.

R: You've certainly shared an awful lot with me, and helped me to understand some of the connections between uh...your beliefs about the world, and life and death and illness, and how the attitudes that you have toward living with cancer...and how those are all underlying all the choices you've made...the strategies of how to live day to day or...you know...how you choose to make your life a good life. They all seem explainable by this underlying faith and attitude. Is that...

FF: mm hmm. I would definitely say so.

MC: Oh there's no question in my mind about that at all.

....................

R: You're saying you feel calm.

MC: That's right.

FF: mm hmm

R: And that this comes from your mental attitude, which comes from your faith. Is that how it all works?

FF: I would think so.

MC: Oh I'd say so.

Their perception that the cancer experience had not changed their lives reflected the degree to which their core beliefs and attitudes defined who they were. While they acknowledged significant changes in many psychosocial aspects of their everyday realities and had developed elaborate strategies with which to approach these changes, the families in this study said they had not permitted cancer to erode the essence of their lives. Rather, they had approached cancer as an experience that must be woven into the fabric of their everyday lives. By using their fundamental sense of themselves as a framework with which to understand and integrate this new aspect of living, the families in this study made sense of their cancer experiences.
Summary

This chapter has presented the families' accounts of their experience of everyday life when an adult member has cancer. In the construction of accounts, families both described and explained their experience.

The accounts described cancer as not having changed their lives. While cancer had an impact on their emotional state, emotional turmoil was not a feature of the families' everyday lives. Although cancer had required role shifts and losses within families, their abilities to compensate with role acquisitions and modifications had prevented these changes from producing disruption. The presence of cancer had also generated new feelings and facts that demanded communication within and outside the families. Further, it had challenged families' philosophical outlooks by presenting them with unanswerable questions and forcing them to acknowledge the mortality of their ill member. Although families recognized numerous instances in which cancer had had significant impact, they retained the perception that their lives were normal lives.

The ability of families to maintain the quality of normalcy in the presence of a major disruptive influence was explained by them in detail. They perceived the choices they had made in their approach to the cancer experience to have minimized the potential impact of the illness. Specific strategies with which they adapted everyday life, evolved a network, managed their medical care, and generated hope were revealed in the process of explaining the family experience. While the strategies included consistencies and inconsistencies between families, all families perceived their own strategic approach to account for the successful
outcome. They further reported that the factor that explained and integrated the structure of strategies and choices they had developed was the attitude with which they had approached cancer. They described this attitude as inherently linked to and arising from their concepts of themselves as families and the tenets with which they had constructed their lives.

This chapter has presented the accounts of the families as they were constructed in the process of collecting and analyzing the data. In Chapter 5, the major findings that emerged from these accounts will be discussed in relation to the research literature reviewed in Chapter 2 and evaluated in the light of relevant theoretical perspectives.
Chapter 5
Discussion of the Findings

Introduction

This chapter will discuss the findings of the study, as presented in Chapter 4, in relation to the view of other theorists and the findings of other researchers. The purpose of such a discussion is to illustrate how current knowledge of the family cancer experience can be enhanced by eliciting the family's perspective.

The research literature reviewed in Chapter 2 established that studies specifically addressing the family cancer experience were scant and inconclusive. The vast body of theoretical literature, also described in Chapter 2, yielded a sketch of current beliefs about what the family cancer experience entails. Since the findings of this study include themes that did not arise from the literature pertaining specifically to the experience of families in which an adult member is living with cancer, additional sources from related bodies of literature and research will be employed in this discussion.

It was not the intent of this study to develop rigorous theory about the family cancer experience. Rather, the study's purpose was to describe and explain the experience from another perspective, that of the family. Thus the organizing framework for this discussion will follow the themes as they were presented in Chapter 4, and the literature will be examined in relation to those themes.
Description of the Impact

General perceptions

The perception of families that cancer had not produced significant change in their lives was an unexpected finding of this study. Miller and Nygren (1978) in their discussion of chronic illness, and Geary (1979) in her examination of family coping, both referred to the process of minimization as a possible explanation of this phenomenon. Both viewed reducing or ignoring the significance of the health problem as a prevalent coping mechanism used by families when confronted with the illness of a member. MacVicar (1975) further suggested that the impact of cancer could result in a distortion of recall, which might account for the families' ability to adopt a perspective that minimized change that had occurred.

In contrast, Speer (1973), in her study of the impact of the husband's illness on family functioning, concluded that the event of severe illness was not sufficient to cause family change. She believed that the capabilities and functions of the members of each family accounted for changes that did occur. The finding of the present study was consistent with some of the accounts in the lay descriptions of personal experience, which also reported that cancer had made little impact on the "nitty gritty" of family life (Abbott, 1981, p. 140).

Impact on emotional state

The emotional reactions described by the families in this study were far less dramatic than would be assumed from a review of the literature relating to the psychosocial aspects of having cancer. As has been previously mentioned, much of the research and theory relies upon the
assumption that cancer invariably constitutes a family crisis (Cohen & Wellisch, 1978; Klein, 1971; Krouse & Krouse, 1982; Livsey, 1980; Moos & Tsu, 1977). Clearly, to the families in this study, the professional construct called crisis would be an inappropriate means by which to describe their cancer experience. However, to a professional viewing these families using an assumed presence of the construct, many of the behaviors and reactions described by families could be perceived in terms of crisis. This discrepancy illustrates a limitation in the usefulness of crisis theory as applied to cancer families.

The specific hazard that triggers crisis in families with cancer has been identified as "death knowledge" (Cohen & Wellisch, 1978). While all families who participated in the present study had experienced an awareness of mortality resulting from cancer, none perceived themselves to have had periods of disruption or disequilibrium that were particularly devastating. While distortion of recall might possibly explain this finding, it seems more likely that the age bracket of the ill members and spouses contributed to a different quality of experience than that reported by younger families. Theorists who address family crisis agree that variables other than the specific hazard determine whether or not a family crisis will occur. Among these variables are the internal and external resources of the family and the degree to which the family defines the hazard as a threat to its status, goals, and objectives (Glasser & Glasser, 1970; Goldberg, 1977). Thus, while crisis theory may provide a useful framework upon which to address the cancer experience in younger families, its utility in relation to older families may be questioned.

A second finding in relation to the emotional state of families was the perception that the emotional impact upon family members was at least
as significant as that upon patients. This finding supports the views of other researchers (Cassileth, et al., 1982; Curtiss, 1981; Hertzberg, 1972), and lends credence to the argument that cancer is, in fact, a family experience.

Impact on roles

As expected, role shifts and changes were common in the families who participated in this study. While the theoretical literature indicated that role shifts generally added stress to the experience a family was already undergoing, the families in this study reported minimal difficulty in making these adaptations. Reeder (1975), in a study of families with a chronically disabled adult, reported a similar finding. She explained this finding as a "retrospective reality reconstruction" whose purpose was to permit families to perceive the change as minimal. G. F. Lewis (1979) reported that role reversal was not uncommon in older families' adaptation to declining health. Thus the age group of the families may have accounted for the ease with which they had been able to make role transitions.

Griffin (1980) described restructuring and reallocation of roles as a means by which families are able to preserve the perception of the ill member as a part of the family system. The findings of the present study indicate that the acquisition of new family roles was successfully employed as a means of minimizing the impact of role losses by the individuals with cancer. Contrary to the findings of MacVicar (1981), who reported that role restructuring lead to tension in families whose usual role allocation conformed to traditional patterns, those families in which male partners acquired new housework duties experienced the change as positive. Thus role loss, rather than role shift or restructure, was the
experience most likely to produce distress in these families. This finding conforms with that of Germain (1979), who perceived the patient's loss of independence to be the major difficulty for both patients and families in the course of the cancer experience.

Impact on communication

The statement by Creech (1975), that having cancer was the modern-day version of having leprosy, was confirmed by the reports of several families in the present study. Untoward reactions from other people were a commonly encountered aspect of the experience. Awareness of the social perception of cancer did not deter families in this study from informing friends and acquaintances of their diagnoses. Whether they discussed the cancer openly with their friends or not, families reported a natural limit to the usefulness of talking with others about cancer. This finding brings into question the commonly held assumption by health care professionals that frank and open communication about the cancer is universally helpful (Benoliel & McCorkle, 1978; Kaplan et al., 1977; MacDonald, 1979; McKhann, 1981). The finding that families believe there comes a time to stop talking about cancer raises interesting questions in terms of the assumptions health care professionals make about the meaning of non-communicative family behaviors. As McKhann (1981) suggests: "Cancer patients do not always want to talk about their disease. Even the very ill have sunshine in their lives, things they enjoy, and often even a sense of humor and perspective about their situation" (p. 54). Certainly the enthusiastic response to the research interviews demonstrated by families in the present study, as in the study done by Green (1982), suggests a strong desire to communicate with others. The purpose of communication, however, may not always be directly related to the subject of cancer.
The vast number of cancer stories acquired by families through their communication with others was another unexpected finding. Van Scoy-Mosher (1978) and Watson (1978) both theorize that negative perceptions about cancer are often related to the family's memory of the experience of cancer in a friend or relative. They describe nursing measures to deal with misconceptions families may have relating to these past experiences. The families in the present study, however, described past experience with cancer as a minor contributor to their impressions about cancer.

**Impact on philosophy**

Distress associated with asking the existential question "Why me?" was a finding of this study. D. H. Johnson (1980) also reported this phenomenon to be an experience of cancer patients in his study. He found that patients reported a specific period of time in which "Why me?" dominated their thinking, although he did not indicate when that time period occurred in relation to the illness experience. Weisman and Worden (1976-77) described the first 100 days of the cancer experience as a distinct phase in which patients were subject to emotional distress associated with such doubt and questioning. Since most of the families in the present study had long passed that first 100 days, it seems possible that the "existential plight" associated with the cancer may be an ongoing or recurring phenomenon.

The direct or indirect acknowledgement of death found in this study is consistent with the statement made by Smith (1975) that cancer is perceived as life-threatening whether or not the victim expects to be cured. Also reported by some of the families in this study was a heightened valuing of life associated with the awareness of mortality. Several lay and professional theorists report awareness of this potential

Explanation of the Impact

The belief that the quality of their lives with cancer was a function of choices they had made was a significant finding in this study. F. M. Lewis (1982) conducted an exploratory descriptive study into the relationship between experienced personal control and psychological well-being in individuals with cancer. She found that cancer patients varied in the degree to which they believed that their own behavior could affect their situation. She also observed that those who did experience a sense of personal control tended to feel less anxiety, a greater self-esteem, and a greater sense of purpose in life than did those who perceived their situations to be a result of forces beyond their control. The fact that the families in the present study saw themselves as having made choices, and described their coping as successful, suggests that the degree of normalcy they were able to achieve in their lives might be a measure of experienced personal control.

Adapting everyday life

To participants in this study, mental attitude made a significant difference in their experience of physical symptoms, particularly those due to chemotherapy. Their belief that fear precipitated side effects, most particularly vomiting, has been substantiated in the health care literature (Altmaier, Ross, & Moore, 1982). Creech (1975) suggests that fear of chemotherapy arises from two widely-held perceptions: its use as a
last resort measure for dying patients, and its power to produce disturbing side effects such as hair loss and virilization. He further reports that "everyone seems to know someone who received chemotherapy..." (p. 290). It is possible that stories about other people's cancer experiences, then, play some part in determining the extent to which such side effects are experienced.

Kelly (1978) theorizes that life with cancer can never be "normal" again. Cassileth and Hamilton (1979) perceive that families with cancer experience a temporary or permanent state of "normlessness." The cancer experience, as described by the families in the present study, did permit the living of a "normal life". Carey (1975), Green (1980), and Hartman (1980) all perceive the attainment of a normal life to be a primary goal for families with cancer. Curtiss (1981), in her study of cancer patients and their spouses, reported surprise at the degree of normalcy with which subjects claimed to live their lives. It seems likely that the lives cancer families described as normal would be defined as departures from normal by those outside the experience. Thus the findings of the present study reinforce the value of defining normalcy according to the criteria adopted by each unique family. Cicourel (1970) believes that normative order in day-to-day family living is "built into what members assume to be known in common and taken for granted in their everyday activities" (p. 168). In this context, the yardsticks for defining normal used by families served as shared reference points for perceiving their lives as normal lives.

The family system disequilibrium, which may result from having planning and future orientation disrupted (Johnson & Norby, 1981), was not found in the families in the present study. Although all participants reported symptoms and treatment regimes that made day-to-day planning
difficult, and also acknowledged that their illness threatened future orientation, they did not all ascribe to the commonly held belief that cancer families should live one day at a time (Kelly, 1978). Interestingly, some families reported that preserving their future orientation represented a consciously chosen coping strategy rather than a denial of reality.

The finding of this study, that families maintained and preserved their usual emotional roles notwithstanding which member was the actual patient, contrasts with the widely held assumption that emotional support flows from family to the patient (Geary, 1979; Hertzberg, 1972). Donley (1978) and Speese-Owens (1981) argue that patients, as members of family systems, should be regarded as both givers and receivers of emotional support. It seems likely that the preservation of usual emotional roles is a more significant determinant of normalcy for these families than is the preservation of instrumental roles. Further, this finding supports the conclusion of other researchers that family members experience the emotional impact of cancer to at least the same degree as do patients (Cassileth et al., 1982; Curtiss, 1981).

This study found that families who chose not to express emotions openly perceived this to be an effective coping strategy. The literature reflects a commonly-held assumption that open expression of feelings is a therapeutic objective (Benoliel & McCorkle, 1978; Hartman, 1980; Kaplan et al., 1977). Further, where lack of communication is observed, it is reported as reflecting denial (McKhan, 1981) or "conspiracies of silence" (Krant & Johnston, 1977-78), both of which are described as pathogenic. Thus the present finding challenges the assumption that any single coping style is universally advantageous. The ability of some families to communicate a non-expressive strategy to the researcher and to each other
is suggestive of a shared understanding rather than a communication problem.

Miller and Nygren (1978) identify displacement/diversion as a general category of coping behaviors commonly employed by cancer families. The findings of the present study elaborate on the meaning of such strategies. Families reported worry and self-pity as powerful threats to their emotional comfort and normalcy. The specific tactics associated with keeping busy and not dwelling on their problems were recognized by these families to be highly effective strategies.

Evolving a network

Parsons (1977) conducted a descriptive study for the purpose of identifying the needs of the intermediate stage terminally ill cancer patient at home. She reported that in her sample, non-family relationships suffered a decline as a result of cancer. The ability of most families in the present study to maintain a social network may be, therefore, a result of the strategies they employed to reduce fear among their friends and acquaintances. MacDonald (1979) believes that a healthy attitude toward cancer implies being able to tell others about it and to use the word "cancer" in the telling. The experience of many of these families supports that belief.

The extent to which cancer families gave meaning to their experience by using it to help others was an unexpected finding. Other researchers have reported the discovery that cancer patients and families welcome the opportunity to participate in research as a means of indirectly helping others (Curtiss, 1981; Fall, 1981; Green, 1982; D. H. Johnson, 1980). Luce and Dawson (1975) provided a partial explanation of this phenomenon. They argued that the North American ethic requires a contribution to the
betterment of fellow human beings before one can leave the world with a sense of accomplishment. They believe that research participation may fulfill this requirement. The families in the present study, however, reported significantly more helping acts than merely participating in research. Humphrey (1978) in his account of experiences prior to his wife's death from cancer, described being astonished at the frequency with which friends sought them out for support. The families in the present study reported a similar experience. Cox (1979) believes that allowing cancer patients to serve as educators and counselors of others may counteract the psychological problems associated with being a passive recipient of health care. It seems likely, then, that the motivation of cancer families to participate in research does not reflect merely a last ditch attempt to contribute, but rather emerges as one aspect of a broader scope of helping acts, the purposes of which may include minimizing the impact of being a help recipient and providing a source of meaning for the cancer experience.

The unique bond that developed between some cancer patients and families was described in the accounts. Ryan and Ryan (1979), authors of a lay account of their family's experience, acknowledge this phenomenon:

Cancer patients have a bond that surpasses a healthy person's understanding. The presence of fear and the agony of pain are transmitted without words by one of us to another. I cannot say how this is done. I only know it happens (p. 321).

The fact that none of the participant families in this study had attended cancer support groups in spite of perceived availability could be explained by their perception that they did not require help. The proliferation of such support groups reported in the literature suggests that where the need for family services arises, support groups are a
popular solution (Johnson & Norby, 1981; Vachon, Lyall, Rogers, Formo, Freedman, Cochrane, & Freeman, 1979). The 1981 study done by Welch found that half of the family members surveyed ranked the establishment of support groups as the least helpful measure of a list of potential health care services. It seems unlikely, then, that the age of the families in the present study accounts entirely for their lack of involvement in such groups. Rather, it appears that many cancer families create networks which fulfill similar purposes yet are not identified as health care services.

An additional intriguing finding of this study was the role that cancer stories played in creating a symbolic network of cancer patients and families. The potency of this network was reflected in the absence of any reports of isolation, an experience that some theorists believe is so common that it is "almost a part of having the disease" (MacDonald, 1979, p. 95). It was a conclusion of Hartman (1980) that lack of knowledge about the day-to-day experience of living with cancer served to reinforce families' feelings of isolation from the rest of the world. Since families may in fact have considerable access to such information about each other, one wonders if the isolation experience is perhaps a reflection of the relationship between these families and the health care professionals they interact with. The notion that a symbolic network may be a factor in the family cancer experience is substantiated by a related finding by Green (1982) that cancer families reported large networks of social support, although quantifiable supportive acts were much fewer. It was her suggestion that the mere symbolic presence of potentially helpful others serves as a type of support system for these families.
Managing medical care

The finding that medical care issues were perceived by families as having a significant impact upon the quality of their living-with-cancer experience was also reported by Green (1982). Clearly, families do not perceive the medical care experience as separate from the everyday experience. Rather, both are viewed as parts of an integrated whole.

The power of health care workers, and most particularly the physician, was apparent in families' accounts of their cancer experiences. The two aspects most relevant to that perceived power were control of information and control of human concern. The need for information has been well documented in the research literature (Hampe, 1975). Fisher, Andrews, Harris, and Martin (1978) in a retrospective study following the death of cancer patients found a significant correlation between difficulty obtaining information and family emotional problems. Green and Adlersberg (1982) suggest that health care workers are conditioned to believe they must have the right answers, and, especially when dealing with families, fear exposure of ignorance or incompetence. It was a finding of the present study that families were well aware that their information-seeking had the potential for placing physicians in a dilemma. Clearly, the strategies used by families to reassure and manipulate health care providers demonstrated that the need to know eclipsed even the strongest reluctance to inform.

The finding of this study that families perceived expressed interest by the physician to be an essential attribute of high-quality health care is consistent with the views of Kleinman, Eisenberg, and Good (1978). They believe that the rigid biomedical view of disease held by most physicians in our society is an inadequate orientation according to most patients and laymen. In their estimation, what patients actually suffer
is not disease, an abnormality in the structure and function of body organs and systems, but rather illness, an experience of disvalued change in state of being and social function (p. 251). Thus, they argue, the assumption by physicians, that biologic concerns are more basic and significant to families than are psychosocial concerns, places the providers and recipients of health care in a conflict of priorities.

Garner (1966) reports that patients do evaluate the care they receive. He further suggests that they perceive listening and understanding on the part of the physician as meeting their criteria for adequate care. Schnaper (1977) supports this view and describes the potential for such expressed interest to minimize suffering even in the absence of a cure. The perception by families that physicians fail to understand this essential component of high-quality care is illustrated by Kaehele (1952) in her account of her own cancer experience:

The conscientious doctor makes an examination, performs a biopsy, and gives up before he opens his mouth to further intimidate the cowering wretch on his table. "Six months," he says, and in six months more or less the obliging patient lies down and dies, never having known that he could do anything else. It is a form of modern-day voodooism, performed by medicine men in sterile white coats fearfully lacking in imagination (pp. 13-14).

The argument that this aspect of health care has not changed significantly in the 30 years since that account was written is supported by the findings of Hampe (1975). She surveyed spouses of terminally ill patients, and reported that only 15 percent of the sample felt that they had received acceptance, support, and comfort from health care professionals.
Welch (1981) theorized that compassion, kindness, and cheerfulness the part of health care providers played a significant part in facilitating hopefulness. The resourcefulness of participants in the present study to facilitate such behaviors in their health care providers illustrates the potency of the need for such expressed human interest.

**Generating hope**

Harker (1972) links the mystery associated with cancer with the fear it evokes in patients and families. Demystification strategies used by families in the present study demonstrated their capacity to find creative measures for minimizing that fear. Families advocated use of the word "cancer" in this capacity. MacDonald (1979) describes using the word freely as a means of enhancing courage.

The degree to which alternative information sources were used by families was an interesting finding in this study. Reports of the phenomenon have not been located in the health care literature. Where alternative information sources are mentioned at all, it is within the context of explaining misconceptions held by lay people (Creech, 1975; Van-Scoy Mosher, 1978; Watson, 1978). This current finding suggests that access to information sources beyond the control of the health care provider may in fact contribute favorably to the family cancer experience.

The finding of this study that some families ascribed to a firm theory of cancer in spite of being informed to the contrary by health care providers is also intriguing. Evidence of behavior change associated with fear of contagion was found in only one participant. Most families reported considerable efforts to re-educate friends who perceived cancer as contagious. Burkhalter (1978) mentioned the myth of contagion as a
popular social belief. Although the potential of the myth for interfering in cancer families' psychosocial experience is self-evident, it seems possible that partial belief in the myth may assist some families to demystify the cause of their cancer. One might postulate that having an unlikely answer to the question "Why me?" is perceived by these families as better than having no answer at all.

Participants in this study described "fighting" as an essential precursor to generating hope. Brainerd (1981) suggests that a "fighting" approach to cancer reduces fear and facilitates a sense of inner strength. Burkhalter (1978) associates "fighting" with the perception of cancer as a challenge. The finding that families perceive "fighting" as having the potential to influence not only quality of life but also the disease itself may reflect the experienced personal control described by F. M. Lewis (1982) and discussed earlier in this chapter. The belief that psychosocial factors may influence tumour evolution has been substantiated to some degree in experiments with mice (Dechambre, 1981). In view of the reported social metaphor of cancer as "a pathology of energy, a disease of the will" (Sontag, 1978), it seems possible that cancer families require "fighting" to achieve a sense of inner strength. The value of "fighting" reported in the literature supports the finding of this study that acceptance of reality without a "fighting" approach is not conducive to hope.

The participants in this study expressed a compelling need to acquire "faith" not only in themselves but also in medical science and in their own doctor. Weisman and Worden (1976-77) report that those who cope well with the existential plight of cancer are those who find something in which to have confidence. Pelletier (1979) describes a phenomenon in patients that is variously referred to as "the faith that heals," "the
will to live," and "the very powerful belief factor" (p. 209). It is his contention that this phenomenon accounts not only for enhanced quality of life but also for increased survival times in cancer. This opinion conforms with the beliefs expressed by families in this study.

Integration of the Experience

A major finding of this study was that families perceived their attitudes to be a key factor in explaining their ability to live a normal life in spite of the presence of cancer. Worden and Sobel (1978) report ego strength at the time of diagnosis with cancer to be closely related to psychosocial adaptation. Further, they report a strong correlation between ego strength and the effective use of coping strategies in their sample of 163 subjects. Spiegel, Bloom, and Yalom (1981) found associations between mastery of the stress of terminal illness and such variables as ego strength, optimism, resourcefulness, and level of life satisfaction. The findings of these researchers support the perception of the families in this study that their attitude did in fact make a difference.

Brooks (1979) laments the dearth of current knowledge about the role of attitudes in coping with cancer. Weisman and Worden (1976-77) suggest an association between pessimistic, regretful attitudes and an emotionally disruptive cancer experience. The description of negative attitudes by families in the present study supports that opinion. It was a finding of this study, though, that although families tended to agree as to what constituted a negative attitude, consensus as to the nature of a positive attitude did not occur. Although the content of a positive attitude varied between families, the properties of that attitude remained relatively consistent. The study found that a positive attitude shaped
the cancer experience in the following ways: it minimized the experience of physical symptoms; it facilitated the building of supportive networks; it augmented the quality of health care received; it provided answers to existential questions; it promoted acceptance of the prospects of terminality; and, it generated hope.

D. H. Johnson (1980) in his descriptive study of chemotherapy patients described major life adjustments in his subjects, "as if previous identities no longer mattered" (p. 33). In contrast, the finding of the present study was that families perceived themselves to be the same as they always had been. Wellisch et al. (1978) and Hartman (1980) suggest that the ability of families to cope with cancer is largely determined by the ability to cope with past experiences. Thus the capacity of the cancer experience to change a family identity may well be a function of the attitude they adopt toward cancer, an attitude which itself is rooted in their history.

The integrating construct with which families in this study explained their attitudes toward the cancer experience, and thus the shape of that experience, was tentatively described as a "family life concept." The ingredients of this life concept were the beliefs and values with which families defined who they were and how they lived. This life concept may be viewed as analogous to the concept of self in individuals. White (1976) describes it as a construct that organizes the individual around the core of bodily sameness and the continuity of memory. He emphasizes its value in understanding the nature of personality. The parallel construct in organizing a family identity is less well understood. McLain and Weigert (1979), however, address a phenomenon they term "family consciousness." They define this as "a fundamental taken-for-grantedness which can be said to constitute a unique family attitude" (p. 173).
Further, they perceive this family consciousness to be a "symbolic universe" that gives meaning and significance to external events and individual existence (p. 183). The findings of this study demonstrate a specific application to finding meaning in the experience of cancer.

A finding of this study was that the presence of attitudes as explanatory frameworks for making sense of the experience was more relevant to the shape of the cancer experience than was the actual content of such attitudes. This finding conforms with the beliefs of other theorists. Hill (1965), a pioneer in family crisis theory, believed that the key to understanding the difference between families who coped and families who did not cope effectively in the face of catastrophe was the "meaning dimension" (pp. 35-6). McCubbin, Joy, Cauble, Comean, Patterson and Needle (1980), in a review of the last decade's theory and research on family stress and coping, agreed with Hill's belief. They concluded that the determining factor did not appear to be the specific meaning the family adopted, but rather the presence or absence of such explanations. Thus the crucial issue appears to be not what sense the family makes of an event, but the fact that it does make sense to them.

McCubbin et al. (1980) and de Give (1980) agree that the role of values and attitudes in constructing family experiences in times of stress has not yet been studied to any significant degree. Since there is little available knowledge upon which to draw conclusions about the findings of this study, one may only speculate as to the relationship between what these families describe and the cancer experience in general.

The apparent absence of crisis, the perception that nothing had changed, and the normalcy of everyday life found in the families in this study may bear some relationship to the stage of life in which they confronted the cancer experience. In her study of cancer families
spanning all adult age groups, Green (1982) reported the following:

Almost invariably older families respond to questions about previous times of change by relating a "philosophy of hard times" which seems to be a value system developed over years of ups and downs. Often the current experience is described as "one more thing" similar to an event in the depression or a previous loss. In short, the current situation seems to be adopted into the fabric of life more quickly than in younger families with less history. (p. 59)

Indeed, the findings of the present study support the perception that the history they bring into the experience explains much of the everyday life of older families with cancer.

Beyond the fact that they have a rich source of history, older families may bring other special attributes to the cancer experience. The psychosocial task of the older adult has been described as that of "ego integrity" (U.S. Department of Health and Human Services, 1980). The older adult is believed to be confronting the issue of meaning in life as he or she approaches death. McCorkle (1976), in her study of terminally ill adults, concluded that those who coped successfully were those who, for various reasons including age, had already accepted the "narrowed focus" to their lives when they encountered the cancer experience (p. 216). In view of the tasks associated with finding meaning in older adulthood, older families might well surpass younger families in their ability to attribute meaning to the cancer experience.

Thus it seems appropriate to surmise that the older family with cancer brings special qualities to the experience. Such qualities not only shape the everyday life of the family, but also permit the family to understand how and why they experience cancer as they do.
Summary

This chapter has discussed the findings of the current study in relation to previous research findings and theoretical literature for the purpose of incorporating the family perspective into what has previously been written about the family cancer experience.

These findings clearly suggest that cancer need not result in crisis or significant family change. While the impact of cancer is experienced in all aspects of everyday life, families are capable of developing strategic approaches with which to moderate or minimize these impacts. The strategies employed may differ from family to family, yet may still facilitate a common group of valued outcomes: minimizing symptoms; evolving networks; augmenting health care; answering existential questions; promoting acceptance; and, generating hope.

This study further found that families perceive attitude to be a key determinant in the shape of the cancer experience. The attitude they describe has its roots in their history and is manifest in the manner in which they define themselves and their lives. The essential attribute of such an attitude is that it integrates the cancer experience into the context of life and provides a sense of meaning. It has been postulated that the special qualities of the older family permit them to shape their cancer experiences in creative ways and also to understand how and why they experience cancer as they do.

The findings of this study also included some intriguing ideas that are not reflected in the research and theoretical literature. The prevalence and significance of cancer stories is one of these findings. Another is the real and symbolic support networks created by the families. A third is the resourcefulness of families in humanizing their health care providers for the purpose of ensuring high-quality care.
Chapter 6

Summary, Conclusions, and Implications for Nursing

Summary and Conclusions

This study was designed to describe and explain psychosocial aspects of the family cancer experience from the perspective of families who were living with cancer in one of their adult members. Holistic family-centred nursing was recognized as an emerging requirement in cancer care. It was further recognized that research-based knowledge about the family cancer experience was an essential foundation for facilitating the provision of such care.

The methodology that directed this study was the phenomenological paradigm of qualitative research. This methodology provided a means by which the researcher could enter into the experience of families living with cancer for the purpose of interpreting it as it appeared to those families engaged in the experience. The method assumes that, through the research act, informants and investigator can construct accounts of the phenomenon that describe the reality with a richness and depth unattainable with quantitative methodologies.

The literature was reviewed for the purpose of identifying findings from previous research into aspects of the family's psychosocial experience with cancer. Since this body of knowledge was found to be extremely limited, a review of common theoretical perceptions about the family cancer experience was also included. From this discussion, general themes were identified and utilized to organize the initial phases of the data-collection process. Thus the literature oriented the investigation
in relation to family emotional state, roles, communication and philosophy.

The data were collected by way of extensive interviews with a total of eight families, each of whom had an adult member currently receiving treatment for cancer at one Oncology Out-patient Clinic. All of the individuals with cancer were older adults. Interviews were audio-taped, and the transcribed verbatim accounts formed the bulk of the data. Data collection and analysis occurred simultaneously through the process of constant comparative analysis. Analytic material was used throughout the data collection process to guide and focus the construction of accounts.

The accounts constructed through the research act revealed three explanatory layers within the family's perception of its cancer experience. The first layer was comprised of a description of cancer's various impacts upon family emotional state, roles, communication, and philosophy. Within this descriptive layer, two contrasting themes emerged. These were the families' perception that nothing had changed as a result of having cancer, and their reports of significant cancer-related changes in everyday life. The remaining layers of the accounts shed light on the meaning of this apparent contradiction.

Firstly, families explained a variety of strategic measures they had chosen in order to preserve normalcy in the presence of cancer. The accounts of their manoeuvres to adapt to everyday life, evolve support networks, manage their medical care, and generate hope illustrated the capacities of these families to minimize and modify cancer's potential impact upon their most valued realities. The final explanatory layer located all of the strategic approaches within the context of attitudes adopted by families toward dealing with the cancer experience. The
accounts also located the attitudes within the context of the families' self-definitions and characteristic approaches toward life. Thus the explanation of the experience in terms of such beliefs and attitudes demonstrated the manner in which families integrated, made sense of, and found meaning in the cancer experience.

The major conclusion of this study is that the key to understanding the family cancer experience is an understanding of the beliefs and values a family uses to define itself and to approach the process of living. The older adults who participated in this study illustrated potent relationships between who they were as families and the way in which they experienced cancer. Their capacity to describe the cancer experience and account for its many aspects suggests that older adults may have a particularly acute capacity not only for adapting well to life with cancer, but also for understanding and explaining its meaning.

A second conclusion is that the attitude a family adopts toward the cancer experience is of major significance not only in directing strategic choices, but also in integrating the entire experience. While attitudes enhance physical and emotional well-being, they also generate external support from both the health care system and the community at large.

A third conclusion drawn from the findings of this study is that cancer may or may not be experienced as a family crisis. Since a preponderance of cancer theory relies upon the crisis model as a common assumption, this conclusion tends to challenge the generalizability of such theory. Families argue that they are capable of considerable adaptation without the assistance of health care services. Rather than crisis intervention or cancer support groups, families need information and human concern from their health care providers.
This study concludes that families with cancer have access to a vast quantity of information arising from sources not controlled by their health care providers. Cancer stories and alternative information sources are widely used not only to evaluate the information they acquire "officially," but also to locate ideas in which they may develop faith and hope.

An additional conclusion of this study is that families differ as to their specific needs and styles. Each possesses its own criteria upon which to evaluate normalcy in everyday life. Each chooses different coping strategies for exerting control over the experience and achieving normalcy.

A final conclusion is that cancer is most definitely experienced within a family context. If the psychosocial cancer experience is to be understood at all, it must be examined as a family experience rather than the experience of an individual patient. While one individual may be the physical bearer of the disease, the entire family lives with the experience.

**Implications for Nursing Practice**

The findings of this study suggest a number of implications for nursing practice. Firstly, nurses must develop skills in assessing, planning, and intervening with family groups rather than isolated individuals if they are to provide responsible psychosocial cancer care. Since cancer families seem eager and willing to talk about their experience, the specific skills required of nurses include asking the "right" questions and listening to the answers. Such appropriate questioning would be that which reflects the fact that families experience
complicated and contradictory realities. Assessment of cancer families should include gathering information about how families view themselves as a unit, how they believe challenges should be approached, and how they define normalcy in their everyday lives. Such assessment should take the maturational stage of the family into account and consider the implications that the maturational stage might have for the experience.

Planning for cancer families should include measures toward facilitating the adoption of attitudes and beliefs about the cancer experience. The appropriateness of attitudes and beliefs should not be evaluated in terms of factual accuracy, but rather in terms of the potential for facilitating faith, hope, and meaning. The efforts of families to find meaning in their experience should be validated and supported.

In administering care directed toward the psychosocial health of cancer families, nurses should avoid assuming that families are in crisis or require external intervention to facilitate their coping. Since dependency on health care services threatens the personal control experienced by families, help should be offered in subtle and tactful ways. Nurses could counteract the negative impact of the help-recipient role by facilitating appropriate circumstances in which cancer families can provide meaningful help to others. Where possible, cancer families should have the opportunity to participate in research, in educational programs, or in one-to-one counselling. Nurses can learn more about the experiences of cancer families and reinforce their sense of control by asking them to share their knowledge.

Where specific services are available for cancer families, support groups should constitute only one aspect of these services. Attention should be paid to creating means for facilitating networking for
families who choose not to participate in groups and lack a cancer network in their social worlds. Since cancer families do seek outside sources of information, nurses should not assume they know only what they have been "officially" told. Further, appropriate resource materials should be made easily accessible to these families.

Nurses who care for cancer families should caution them against adopting coping strategies simply because they worked for someone else. Since lay and professional cancer resources tend to assume specific strategies are universally helpful, families may experience distress if such information is not adequately filtered. Rather, families should be encouraged to evaluate the utility of suggested strategies in terms of their own beliefs and values.

Finally, the nurse should adopt a family advocate role, particularly in relation to the family's need for information and human concern. Beyond attending to these needs herself, the nurse may need to educate other health care professionals as to the mutual benefit of meeting such needs.

It is apparent that the findings of this study provide a basis upon which to facilitate an understanding of nursing's potential role in the care of families with cancer. Obviously, much more research-based knowledge would be required before a comprehensive understanding of the family cancer experience could be achieved. Implications for nursing research will be discussed in the following section.

Implications for Nursing Research

This study has demonstrated the potential for conducting research that addresses family groups rather than individual members. Although it
is likely that the data obtained from research on family groups differs from that obtained from the members separately, the latter need not be viewed as the only manageable information source. Certainly, studies that include data collection from both the family unit as a whole and the individual members separately might be an illuminating source of additional understanding about family dynamics. The phenomenological paradigm of qualitative research provides a valuable method for establishing a general knowledge base about families in a variety of life circumstances. Since the findings of this study did challenge some commonly held assumptions about what families might experience, it seems appropriate to suggest the need for extensive qualitative exploration into family life before productive hypotheses about families are formulated.

The findings of this study suggest a number of implications for further research into the cancer family experience. Since this study based its findings on the accounts of older adults, similar studies with families in different maturational stages would shed light on the degree to which the findings of this study reflect the experience of older adults rather than the general family cancer experience. Further, since the findings of this study included phenomena that were not reported in the literature, it seems appropriate to suggest that qualitative methodologies are highly appropriate to the general question of what families experience at this point in the evolution of knowledge.

Specific issues within the findings of this study also lend themselves to further qualitative study. Kleinman (1977) advocates the study of explanatory models of the definition and meaning of illness for families. This study demonstrated a relationship between explanatory models of illness and the family's explanatory model of itself as seen
through a perceived "life concept". The nature and relationship of such explanatory models deserves serious consideration in future research.

The meaning and prevalence of the cancer story phenomenon is a theme worthy of future research attention. A related theme, that of cancer networking, is another area in which qualitative research would be fruitful. Since such phenomena appear to represent mechanisms by which families regain control over their beliefs and their ability to hope, further exploration of their meaning might illuminate perceived inadequacies of the current health care system and establish the value of health care system control in the illness experience. Such understanding would provide an intelligent basis upon which to plan programs for cancer families that meet their needs without eclipsing the external networks of support and information they create on their own.

The finding that access to information and degree of concern are the primary criteria by which cancer families evaluate their medical care suggests a need for further research. Studies that locate specific sources of health care satisfaction might add strength to the argument that disease-oriented care is counter productive in cancer therapy.

Since families in this study adapted effectively through the use of contrasting strategies, further study into general and specific coping tactics seem indicated. Research into specific coping mechanisms might be fruitful in determining other factors that influence their effectiveness. Isolation of variables that determine the fit between the family and the specific strategy would greatly benefit the capacity of helpers to facilitate family coping.

A final issue requiring further study is the utility of the crisis model in approaching cancer. Retrospective and longitudinal studies of
cancer families could yield valuable data as to predictive factors associated with the incidence of crisis in cancer. Since it seems likely that attitude, meaning, and philosophy of life play some role in mediating the threat of family crisis, particular research attention should be paid to those elusive yet essential variables.

In conclusion, the family cancer experience has not yet received the attention it deserves in health care planning and research. Much more knowledge is required before the health care professions can appreciate the complexities of helping, without jeopardizing, family adaptation in the cancer experience. At present, the only viable source of essential knowledge and understanding is the expert witnesses who have experienced life with cancer in the family.
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Appendix A

Information and Consent Form

My name is Sally Thorne. I am a registered nurse doing Graduate work at the School of Nursing, University of British Columbia. Since September 1981, I have been associated with the Outpatient Oncology Clinic at [ ] Hospital. My experience at the Clinic lead to my interest in learning more about what a family goes through when one member has cancer. The way I hope to learn more about this is to interview some of the families in which one member is currently under the care of Dr. [ ].

If you and at least one other member of your family agree to participate in this study, I will arrange a convenient time for an interview, probably in your home. I will then ask you and your family questions about changes in day to day routines, household responsibilities and outlook on life since you were diagnosed as having cancer. I will invite you to share with me any of your ideas about how cancer affects a family. If you wish, you may refuse to answer any questions during the interview. The interview will be tape recorded, but every effort will be made to avoid using names or identifying information on the tape. The only people who might listen to the tape will be myself and my thesis advisors. Excerpts of the interview might be included in written reports of my study, but again, no names or identifying factors will appear. Upon completion of my study, the tapes will be erased. My reasons for requesting tape recording of interviews are that it will enable me to seriously consider any concerns or issues expressed by your family, and to compare them with the ideas of other families participating in the study.
Approximately six weeks after this initial interview, I would request a second family interview for the purpose of clarifying issues you have raised and avoiding any misunderstandings. This interview would be conducted and recorded in the same manner as the first.

Whether you participate in this study or not will have no effect whatsoever upon your treatment and care in Dr. [ ]'s clinic. If you agree to participate, then later change your mind, you will be free to withdraw your consent. Although I would prefer to include anyone whom you consider to be a member of your family in the interview, each member's right not to participate will be respected at any time.

I anticipate that the benefit of this study will be to help me learn more about what families experience when a member has cancer, so that I can communicate this knowledge to others involved in working with families living with cancer. If you have any questions about the study or about what to expect if you decide to participate, please feel free to contact me through the nurse clinician at [ ] Hospital's Out-Patient Oncology Clinic.

* * * * *

I have discussed the nature of this study with my family and we have agreed to participate.

__________________________  ________________________
   date                  signature of patient
Appendix B

Sample Questions for Initial Interview

1. What has it been like for you as a family to have a member with cancer?
2. What are the major things that have happened to your family since (name of patient) was diagnosed with cancer?
3. How has (name of patient)'s having cancer affected your family life?
   - (if clarification necessary) I am especially interested in such things as day to day routines, who does what around your house, things you do together as a family.
4. In your opinion, what is it about the cancer experience that accounts for these changes?
5. Has your family ever experienced anything that affected you this way before?
   - If so, how is this cancer experience similar or different?
6. Has having a member with cancer affected your family's outlook on life in any way?
   - If so, how or why do you think this happens?
7. What is it like for you to talk about the experience?
   - (if clarification necessary) What kinds of things do you talk about within your family in relation to the cancer? How does it feel to talk about what you are going through to people outside of your family?
Dear

I am a graduate student in Nursing at U.B.C. As one part of my thesis research I have been interviewing families to find out how they are affected by the fact that one of their adult members is living with cancer. On [date], I spent some time with your parents, and they shared their views about the subject with me. They also asked that their children be given an opportunity to tell their side of the story, and gave me your address.

The information I am gathering from families in my study is generally anything they wish to tell me that would illustrate how having cancer in the family affects members' outlook on life, day to day activities, and relationships within the family and with people outside the family. It is my belief that if health care workers better understood the family experience, we could help families with cancer live better. If you are interested in sharing with me any of your ideas or stories, I would be very pleased to receive them.

Please understand that you are under no obligation to reply to this letter; it is merely an invitation to contribute to the research if you so desire. Any replies will be treated as confidential, and anonymity of information is assured. If you decide you would be interested in making a contribution to my knowledge of the experience, please jot down your ideas and send them to the address above.

Yours sincerely,

Sally Thorne, R.N, B.S.N.