

The Experience of Families When a Child is Diagnosed with  
Cancer with a Favorable Prognosis

by

Laura Clarke-Steffen

A Doctoral Dissertation

Presented to

Oregon Health Sciences University

School of Nursing

in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy

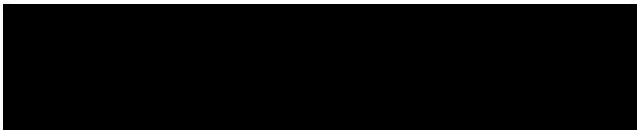
May, 1990

Approved:



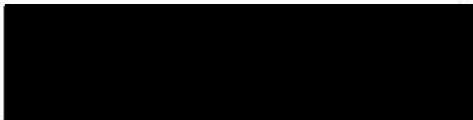
---

Sheila Kodadek, RN, PhD, Associate Professor,  
Dissertation Chair



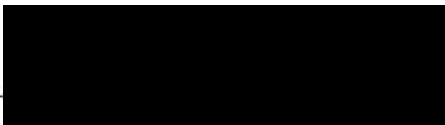
---

Barbara Limandri, RN, DNSc, Assistant Professor,  
Reader



---

Barbara Valanis, RN, DrPH, Adjunct Faculty,  
Reader



---

Carol Lindeman, RN, PhD, FAAN,  
Dean, OHSU School of Nursing

This research was supported, in part, by Public Health Service National Research Service Award # NR06157, through the National Center for Nursing Research; the Sigma Theta Tau, Beta Psi Chapter, Research Award; and the Focal Area III, Oregon Health Sciences University, School of Nursing Small Grant.

## Acknowledgements

My advisor, Sheila Kodadek, has been a constant support behind this dissertation. She has had the unique ability to push me when I needed it, to back off when I needed a break, and to ignite my thinking when I became stuck. I appreciate the fact that she has made herself available for consultation whenever necessary. My other committee members have added also to this research effort. Barbara Limandri has been helpful in solving some clinical situations and in dragging the theory kicking and screaming from the data. Barbara Valanis has given her critical remarks and knowledge of cancer to the formulation of this dissertation.

For the completion of this study, I am most indebted to the families who were willing to share their lives with me by participating in this study. They willingly gave of their time and themselves by telling their stories and welcoming me into their homes.

I would like to mention for their help with technical assistance, Carol Holt and Bev Rogers. In addition, Martha Haylor was instrumental in coding the interviews.

I would like to thank Linda Birenbaum, whom I worked for as a research assistant as I began my doctoral education. She has done much toward shaping my research interests and abilities, setting an example of tireless questioning and questing for knowledge. She also provided the emotional support needed to take on the arduous role of researcher.

Several members of my family have also provided the love and support necessary to take on a project such as this one. Thanks to my husband, Bob, for

his chauffeuring aid during the data collection, for the many hours he spent in the library photocopying articles and for his continued support and confidence in me. Thank you also to my parents, Milton and Dorothy Clarke, and Gordon, Ginny, Doug, Carolyn, Rob, Bianca, Jeff, Jane, Traci, Brandon, Ryan, Lindsey, and Bruce. Without their support, I do not think I would have finished this program.

Finally thanks are due to Brandy, Jonathon, and Jimmy who first caused me to question how families experienced the diagnosis of and transition to living with childhood cancer.

## TABLE OF CONTENTS

	Page
List of Tables. . . . .	viii
List of Figures. . . . .	ix
Chapter 1 Introduction. . . . .	1
Significance of the Problem. . . . .	1
Transition Perspective. . . . .	2
Symbolic Interaction and Grounded Theory. . . . .	3
Definitions. . . . .	3
Chapter 2 Review of Literature. . . . .	5
Introduction. . . . .	5
Illness Experience. . . . .	5
Family Members' Responses to Childhood Cancer. . . . .	6
Transitions. . . . .	29
Summary. . . . .	44
Chapter 3 Methods. . . . .	48
Assumptions. . . . .	48
Design. . . . .	49
Setting. . . . .	49
Sample. . . . .	50
Interview. . . . .	60
Procedure. . . . .	62
Ethical Issues. . . . .	65

Analysis. . . . .	67
Limitations. . . . .	70
Chapter 4 Analysis: Family Transition to Living with Childhood Cancer. . . . .	72
First Clue. . . . .	74
Limbo. . . . .	78
Strategies Used to Reconstruct Reality. . . . .	86
New Normal. . . . .	113
Timing of the Transition. . . . .	119
Chapter 5 Discussion and Implications. . . . .	121
The Family Transition to Living with Childhood Cancer. . . . .	121
Implications for the Delivery of Nursing Care. . . . .	137
Implications for Research. . . . .	144
Methodological Implications. . . . .	145
Summary. . . . .	151
References. . . . .	155
Appendices. . . . .	166
Appendix A: Interview Schedules. . . . .	166
Appendix B: Family Information Sheet. . . . .	173
Appendix C: Consent Forms. . . . .	176
Appendix D: Family Interview Code Sheet Example. . . . .	185
Appendix E: Family Transition Summary Sheet. . . . .	190
Abstract. . . . .	192

## LIST OF TABLES

Number		Page
1	Transition Concept Delineation by Perspective. . . . .	30
2	Characteristics of the Families. . . . .	52
3	Characteristics of the Fathers. . . . .	53
4	Characteristics of the Mothers. . . . .	53
5	Characteristics of the Ill Children. . . . .	54
6	Characteristics of the Siblings. . . . .	55
7	Favorable Prognosis Cancer Diagnoses and Disease Free Survival Rates. . . . .	59



## LIST OF FIGURES

Number	Page
1 Family Transition to Living with Childhood Cancer. . . . .	73
2 First Clue. . . . .	75
3 Managing the Flow of Information. . . . .	93
4 Managing the Medical Regimen. . . . .	102
5 Assigning Meaning to the Illness. . . . .	108
6 New Normal. . . . .	114

## INTRODUCTION

### Significance of the Problem

Childhood cancer is the leading disease cause of death for children under 15 years of age (Silverberg & Lubera, 1988). There are an estimated 6,000 new cases of childhood cancer diagnosed each year in the United States (American Cancer Society, 1985). With current five year survival rates of 60% or better for all childhood cancers combined, significant numbers of children are being treated for cancer. In addition, the literature suggests that the consequences of childhood cancer, necessitating continuing health care, are still present many years after treatment ceases even when the child survives the illness (Jaffe, 1984; Koocher & O'Malley, 1981).

In recent years, treatment advances have resulted in long-term survival for the large percentage of children with cancer with a favorable prognosis. This is considered by some to be a cure (Mauer, 1987; Pinkel, 1987; Podrasky, 1986). For example, for some subtypes of leukemia, Wilm's Tumor and some types and stages of lymphoma, 5 year survival rates are greater than 60% (Coccia, 1983). Those children who have a good prognosis at diagnosis and who respond well to treatment have a very different illness career or trajectory than those with a less favorable prognosis. It is hypothesized that children and families experiencing this type of prognosis may have a different type of response than families faced with a greater certainty that the child's illness may be fatal. For example, Koocher & O'Malley (1981) discuss the effects of ambiguous outcome on long-term survivors and their families.

The impact of childhood cancer on the family has been and continues to be an object of study and concern (Binger, Ablin, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969; Bozeman, Orbach, & Sutherland, 1955; Koocher & O'Malley, 1981; Spinetta, 1981). That the diagnosis has the capability of effecting changes in the family is practically undisputed, and it has been remarked that virtually no family is unchanged by the diagnosis and subsequent treatment (Gogan, O'Malley, & Foster, 1977). Families whose child has been disease free and off treatment for a year have reported that the time immediately after diagnosis is the most stressful, the most demanding of change, and the time when families are in most need of intervention (Clarke, 1986).

Family response to childhood cancer is a nursing concern because it affects the health care measures taken by family members on behalf of the ill child. Family response also affects the psychosocial environment in which the child must continue developing despite the illness. In addition, family response affects the health and adjustment of all other family members (Cohen, 1985; Fife, Norton, & Groom, 1987).

#### Transition Perspective

The purpose of this study was to describe the process the family engages in while moving through the transition of becoming a family experiencing favorable prognosis childhood cancer. For the purpose of this study, a transition perspective was chosen to view family response to the diagnosis of childhood cancer. This perspective allowed assessment of the transition within the context of long-term change and alteration of individual and family structures. The

family response was viewed as interactive, dynamic, and a process which occurs over time, rather than isolated variables for isolated individuals measured at isolated points in time.

### Symbolic Interaction and Grounded Theory

Symbolic interaction was used as an assumptive world from which to view the transition perspective. Symbolic interaction posits social construction of meanings through interaction which individuals interpret to guide their own behaviors and actions (Blumer, 1969). Within this framework, family members were seen as deriving meanings of the illness and the process of response to the illness through their symbolic communication. The processes of communication and response were believed to be important components of a transition, and were objects of the present study. Symbolic interaction suggests qualitative methods (Blumer, 1969), and particularly grounded theory to study process phenomena. Therefore, a modified grounded theory method of data collection and analysis was used.

### Definitions

In order to clarify the discussion of the transition following the diagnosis of a child with cancer, the following definitions are provided:

Transition perspective—refers to the accumulated theoretical and research literature as to the nature of the passage, movement, or change from one position or state to another.

Transition process—refers to the dynamic process which occurs when an individual moves through a series of changes in passage from one position or

state to another. The transition process is characterized by disequilibrium and disorientation which stimulates the restructuring of the cognitive and emotional world in response to a critical event or series of events. This process is further described in the review of literature.

Response to transition—refers to the outcome of the passage, movement, or change from one position or state to another, with a stable state following the period of disequilibrium. This term also refers to the person's emotional, mental, and physical reaction to the process of moving from one state or position to another.

## REVIEW OF LITERATURE

### Introduction

The focus of this study is the experience families have and processes they engage in as they move through the transition of becoming a family with a child with cancer. This review of the literature will address the experience of childhood cancer, first in the United States, then from the perspective of individual family members and finally from the perspective of the family unit. Family response to diagnosis of a serious, life-threatening illness in childhood has been assumed to be a transition (Chick & Meleis, 1986; Quint, 1969). Therefore the literature defining and describing transitions will also be reviewed. Response to transition will be the expression used in this review of the literature to denote a changed pattern or level of functioning resulting from the challenge presented by the diagnosis of childhood cancer.

### Illness Experience

Currently, care for the majority of children with cancer is coordinated primarily at major pediatric cancer centers, using national investigational protocols. Treatment is managed primarily on an outpatient basis. A child may be admitted to the hospital only at the time of diagnosis and never be readmitted. For families living great distances from the major medical centers, a local physician may administer much of the treatment under the direction of pediatric oncologists at a larger medical center. Two treatment modalities became common in the 1980's and continue to be used today. Bone marrow transplants are a viable and successful treatment option for many children with

a variety of cancer diagnoses (Kadota & Smithson, 1984; Quinn, 1985). And home care for the seriously ill child is a widely used option with many potential effects on the family unit (Bakke & Pomietto, 1986). For example, as a result of the advances and changes in treatment, frequently a child will go home with a permanent vascular access device, intravenous pumps and/or a complex medication regimen, all of which must be managed at home.

Open communication is a philosophical tenet of psychosocial care. Most ill children and their siblings know the name of the illness and the purpose of the treatments. A large number have some concept of the seriousness and potentially fatal outcome of the illness. Long term physical, emotional, and social sequelae of childhood cancer for the ill child are important topics for current research (Byrne, J., et al., 1989; Koocher, O'Malley, & Foster, 1981; Koocher, O'Malley, Gogan, & Foster, 1980). In addition, there is a growing body of research about effects of the chronicity of the illness on the family (e.g. Birenbaum, 1987a; Cairns, Clark, Smith, & Lansky, 1979; Johnson, Rudolph, & Hartman, 1979; Koocher & O'Malley, 1981; Lavigne & Ryan, 1979).

### Family Members' Responses to Childhood Cancer

#### Child's Initial Response

##### Intra-individual Aspects

The ill child experiences multiple physiological (Sutow, Fernbach, & Vietti, 1984), intrapsychic (Spinetta, 1977), and social changes during the course of the cancer illness. The first physiological change occurs independently of and prior to the diagnosis of the disease. In fact it is often this change that triggers the

family to seek medical advice and thus occasions the diagnosis (Sutow, et al., 1984).

Shortly after diagnosis the child faces other physiological changes and disorganization caused by chemotherapy, surgery, or radiation therapy, all of which alter the metabolic organization to decrease support of the malignant cells. This disorganization is marked by visible signs such as loss of hair, weight loss or gain, loss of a limb, or disfigurement from prednisone, as well as loss of tumor burden. The physiological disorganization leaves the child with depleted energy stores to invest in the process of moving through the psychological and social changes that also accompany the diagnosis of childhood cancer.

Initially the individual response is characterized by disruption which takes the form of anxiety (Kupst & Schulman, 1980; Peck, 1979; Spinetta, Rigler, & Karon, 1973), anger and aggression (Geist, 1979), cooperation with hospital staff (Kupst & Schulman, 1980), depression (Friedman, 1967; Geist, 1979; Hoffman & Futterman, 1971; Peck, 1979), worry and apprehension (Karon & Vernick, 1968), and communication with staff (Kupst & Schulman, 1980). Isolation to reduce risk of infectious disease may further exacerbate withdrawal and depression in some children (Kellerman, Rigler, & Siegel, 1977). Denial is a well documented response and hence part of the process of transition to being a child with cancer (Hoffman & Futterman, 1971; Koocher & O'Malley, 1981).

The ill child experiences a loss of healthy body, present and future abilities, self, and body image. This loss is thought to result in mourning. It is felt that



withdrawal from the lost entities must occur before the child can mobilize coping abilities (Geist, 1979).

Whether any of these responses to the illness is functional or dysfunctional for the child is an issue that has been debated in the literature (Binger, et al., 1969; Greenberg, Kazak, & Meadows, 1989; Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980). It is possible to view responses that in the short-term appear to increase disorganization as contributing factors or necessary preconditions for later growth producing reorganization.

#### Social Role Aspects

When the diagnosis is made and revealed, the child experiences the new role expectations of an ill child rather than the well child role expectations of a few short days or weeks ago. There may have been some anticipatory preparation for this role change when the child was hospitalized or when symptoms presented themselves. The new role will have implications for the child's school attendance (Deasy-Spinetta, 1981), for frequency and type of interaction with peers, for the child's appearance, and for his/her self-concept. The child must learn new behaviors with nurses and physicians for new stressful, painful activities such as physical examinations, sophisticated imaging techniques, bone marrow aspirations and spinal taps experienced during frequent clinic and hospital visits. In addition, the familiar role expectations of the parent-child relationship may be drastically redefined by the parents as they struggle with their own transition to the child's cancer. Consequently, the child may experience alternate approach and withdrawal behaviors on the part of the

parents and must adapt his/her own behavior accordingly. Geist (1979) hypothesizes a loss of role within the family and subsequent mourning on the part of the ill child. Mourning continues until the ill child is able to renegotiate and redefine his or her role within the family such that the child perceives that role as making a positive contribution to the family. It must be commented that this is contrasting simultaneously with expectations that the ill child be treated "as normally as possible".

### Parent's Initial Response

#### Individual or Intrapsychic Aspects

Parents also experience a change and disruption, described as "a shattering of worlds" or a "shattering of reality" (Chen, 1988; O'Brien, 1988), when the child is diagnosed with cancer. Their transition is primarily of a social and intrapsychic nature. Within the individual, the process of becoming a parent of a child with cancer is characterized by initial shock, guilt (Friedman, 1967; Johnson, et al., 1979), denial, anxiety (Fife, et al., 1987; Kupst & Schulman, 1980; Magni, Messina, De Leo, Mosconi, & Carli, 1983; Magni, Carli, De Leo, Tshilolo, & Zanesco, 1986; Magni, Silvestro, Carli, & De Leo, 1986), depression (Kupst & Schulman, 1980; Magni, et al., 1983; Magni, Carli, et al., 1986; Magni, Silvestro, et al., 1986), anger (Friedman, 1967), obsessive-compulsiveness in the form of preoccupation with the illness (Magni, et al., 1983; Magni, Carli, et al., 1986; Magni, Silvestro, et al., 1986) and grief (Lansky, 1974). Guilt is not universally seen. Kupst and Schulman (1980) found less

than 50% of the parents in their study expressed guilt, and attributed the lack of guilt to preoccupation with fitting the child's treatment into their lives.

Denial usually is in reference to the long-term consequences of the illness and for the majority of parents does not interfere with decisions to have the child treated appropriately. In some cases extreme denial is believed to cause the parents to seek multiple opinions and to try treatments that have not been proven effective by conventional standards (Chodhoff, Friedman, & Hamburg, 1964; Natterson & Knudson, 1960).

Anxiety is perhaps the most universally experienced symptom of the disruption caused by the diagnosis of cancer in one's child (Bozeman, et al., 1955; Fife, et al., 1987; Kupst & Schulman, 1980; Powazek, Payne, Goff, Paulson, & Stagner, 1980). Johnson et al. (1979) and Van Dongen-Melman and Sanders-Woudstra (1986) attribute this to the continued connection of cancer with death.

Depression is an expected response; one commonly cited explanation is that the parent has lost the perfect child he/she thought he/she had. A grief reaction follows this loss. In addition, some authors write that anticipatory mourning for the child's death begins with the diagnosis and knowledge that the illness is potentially fatal (Futterman & Hoffman, 1973; Natterson & Knudson, 1960). With more recent successes in treatment of many childhood cancers, information presented to parents is more optimistic, and anticipatory grief reactions may not be so prevalent or intense, although no one has systematically investigated the effect of positive information on anticipatory

grief. Certainly, even if the illness is not necessarily fatal, the diagnosis of a chronic illness such as cancer can and does induce depression and grief in the parents and those effects are still evident in several recent studies (Kupst & Schulman, 1980; Magni, et al., 1983; Magni, Carli, et al., 1986; Magni, Silvestro, et al., 1986).

#### Social Role Aspects

Becoming the parent of a chronically ill child greatly adds to the role expectations of the parental, caretaking role. Many of the new role expectations are not normative for the parents of well children, yet are demanded of the small subset of parents who have an ill child. The multiple demands on the parents at a time when they are struggling to adjust on a personal level to the fact that a beloved child has an impairment that may be fatal produces a great amount of role stress.

Parental role behaviors expected at this time are the maintenance of an attitude that is supportive for the child (Johnson, et al., 1979); wise decision making about treatment for the child; support of the spouse; and reorganization of family life so that others in the family are provided for during the sick child's hospitalization or clinic visits. One or both of the parents must communicate the fact of the illness to the remainder of the family, to someone in the work place, and perhaps to others in the social network. There is some expectation that in the process of communicating this information, the parent will be comforting to extended family and open to discussion of worries and concerns with the ill child's siblings.

At the same time, the parent must negotiate role behaviors with professional health care providers. It must be determined how much authority the parent holds over the child while in the hospital. The parent must learn the appropriate behaviors to be used in gaining information from professionals (Kupst & Schulman, 1980) and asserting needs without challenging the professional's expertise. In addition, the parent often meets the parents of other children with similar diagnoses, and must negotiate relationships with them. One study has found that these relationships are helpful for the parents (Wells, Heiney, Swygert, Troficanto, & Stokes, 1989).

Simultaneously, the parent must negotiate with the ill child a new parental role. Discipline is a particular area in which this negotiation is most obvious. The parent initially noticeably eases up on or becomes overprotective of the child (Johnson, et al., 1979). Subsequently the child tests the limits of this permissiveness or restrictiveness, to the point that the parent does intervene. The point of intervention may not be consistent at first. However in moving through the transition, most children and parents will arrive at a stable arrangement of disciplinary boundaries, albeit different from before the illness.

#### Sibling's Initial Response

It is recognized that the diagnosis of cancer in a child presents a stressor to the siblings of that child. Literature about siblings is difficult to interpret in relation to initial responses versus long-term adaptation because samples commonly consider the two groups together and treat them as homogeneous. A discussion of sibling response over the entire illness trajectory will be given here

followed by a report of literature regarding sibling response during the diagnostic phase. Studies of response during the remission phase will be reviewed in a later section of this paper.

The stressor of childhood cancer most often requires that siblings of the ill child restructure their life-style, particularly interpersonal relationships within the family (Cairns, Clark, Smith, & Lansky, 1979; Iles, 1979). In restructuring life-style and family relationships, most siblings are able to adapt successfully and exhibit no emotional or physical health deviations as a result (Chodhoff, et al., 1964; Friedman, Chodhoff, Mason, & Hamburg, 1963; Lascari & Stehbens, 1973; Stehbens & Lascari, 1974). However, some siblings are not able to restructure their life-styles successfully, and are at risk for developing subsequent health problems (Binger, et al., 1969; Birenbaum, 1987b; Krell & Rabkin, 1979; Maguire, 1983; Spinetta, 1981; Tietz, McSherry, & Britt, 1977). Several sources report that siblings are often neglected (Anderson, 1981; Maguire, 1983; Spinetta, 1981). Although usually not physically neglected, the sibling does not have the close relationship with the parents that is considered optimal for the child's emotional development (Maguire, 1983; Sourkes, 1980; Tietz, et al., 1977). This is thought to be due to the parents' extensive time away from home and their preoccupation with the ill child and the management and outcome of the cancer treatment. This may result in the parents not being aware of insidious physical or emotional health problems (Maguire, 1983; Spinetta, 1981; Tietz, et al., 1977).

During the time that the child with cancer is undergoing treatment, the family is frequently in contact with the health care system. However, the siblings may not receive professional attention, either for the purpose of determining the existence of possible problems or the treatment of mental and social health problems. It is probable that this is due to the parent's concern being focused on curing the ill child (Maguire, 1983). It is apparent that the siblings of children with cancer are an available, vulnerable population that could benefit by the intervention of nurses in assessing their health status and promoting their health.

In a study of the impact of the illness on the family, Binger, et al. (1969) found that parents reported emotional disturbances requiring psychiatric help in 11 of 16 families interviewed after the death of the child. Other families reported milder disturbances. Over half of the children in these families were reported by the parents to exhibit significant behavioral problems and somatic complaints. The problems were not compared with incidence or severity of similar problems in the population of normal children. In contrast, Stehbens and Lascari (1974) in a study interviewing parents after the death of a child, reported that 37 of 40 parents resolved all symptomatology by six months after the death. In this same study, the parents reported that 70% of the siblings were "back to normal within a week". This latter finding raises some concerns about the validity of the measure of sibling health problems used in this study, since other descriptions of the bereavement process suggest that the effects of bereavement in childhood last longer than a week (Birenbaum, 1987b).

In contrast, Tiller, Ekert and Rickards (1977) report that behavioral problems in the ill child were common. There were additional studies citing health problems, particularly behavioral problems, among the siblings (Tietz, et al., 1977; Tiller, et al., 1977). Spinetta (1977) recommended that problems among all family members could be ameliorated with open communication about the illness and its consequences among the family members.

In addition to looking at the research on response of siblings to childhood cancer in its historical perspective and effects of the entire illness experience on the health status of siblings, studies of effects of childhood cancer on siblings may also be classified by the phase of the illness trajectory at which the family is during the time of the study. Some studies have looked only at the terminal or bereavement phases (Binger, et al. 1969; Kaplan, Grobstein, & Smith, 1976). Most of these studies depend on parent reports of sibling health problems as the source of data. Parent reports are biased in that parents may not be aware of subtle mental health problems or may exaggerate problems that the children are experiencing. Many studies that look at sibling response during other phases of the illness trajectory also depend on parent interviews to supply the data (Chodhoff, et al., 1964; Friedman, et al., 1963; Johnson, et al., 1979; Kaplan, et al., 1976). Because many of the studies are preliminary in nature and use parent report as the major source of information interpretation is difficult.

Several studies have looked at sibling response from the sibling's point of view through the use of open ended interviews with siblings themselves (Cairns, et al., 1979; Koch, 1985; Koch-Hattem, 1986; Koocher & O'Malley, 1981;



Kramer, 1984). The findings from these studies suggest that indeed siblings are at risk for developing problematic responses.

The literature also suggests several factors that influence the development of problems in siblings of children with cancer. Age and sex, with males aged 7–13 most at risk (Lavigne & Ryan, 1979), are suggested in some studies as variables that are associated with development of emotional problems in siblings (Lavigne & Ryan, 1979; Spinetta, 1981).

Family communication about the illness process and family functioning have also been suggested as intervening variables in the response of siblings to childhood cancer (Birenbaum, 1987b, 1989; Spinetta & Deasy-Spinetta, 1981). A consistent philosophy of life and the meaning of the illness, social support, and disease related communication with the ill child were found to predict post-death family adaptation (Spinetta, Swarner, & Sheposh, 1981). Parental communication with the siblings was not found to be a statistically significant predictor of the overall family adaptation. This study does not examine the effects on the sibling or the effects on possible combinations of relationships between two or more family members. These variables need to be considered in the measurement of sibling emotional and health problems and the identification of those siblings most at risk for developing problems.

Summarizing and interpreting the findings in the literature, it can be stated that problems arise in the response of siblings of children with cancer, particularly problems with social competence and mental health. Whether the incidence of health problems is greater than in the normal population is not

clear. Certain methodological problems such as using parent reports to open-ended questions and collecting data after the ill child has died could explain differences in findings.

#### Family Unit Initial Response

With the diagnosis of cancer in one of the children the family undergoes a transition. Anecdotally and clinically, it is apparent that during the times when the child is hospitalized, the family must be reorganized to accomplish tasks such as nourishment and protection while one or both parents are absent from the house for long periods of time. The emotional needs of the siblings must be met also (Koch, 1985), as must the needs of the marital dyad. The everyday needs must be met, as well as additional needs brought on by the child's illness. For example, siblings worry about the ill child, whether they also may be susceptible to cancer, and the apparent neglect of their parents. They may, concurrently with their concern for the ill child, experience feelings of jealousy at the extra attention, privileges, and material goods that are given the ill child. In the redistribution of family roles, siblings may take on additional caretaking responsibilities for the ill child (Koch, 1985).

The marital relationship is also disrupted. One study reported marital satisfaction scores as lower than a sample of normal couples, but higher than scores of couples in therapy (Fife, et al., 1987). Sometimes the disruption is related to different coping styles and simultaneous needs of the partners for different types of support in coping with the meaning of the child's illness. Sometimes the disruption is occasioned by perceived inequity in division of

illness related tasks. Other times the disruption is influenced by the separation of the partners as one may be out of town or out of the home with the hospitalized child. Clinical observation has demonstrated that at the time of diagnosis some married parents seriously evaluate the possibility of divorce in light of the child's illness. Likewise, separated and divorced parents have been noted to consider reuniting because of the child's illness. It has also been reported that ill children sleep with one or both of the parents which may disrupt the marital relationship.

Magni, Silvestro, Tamiella, Zanesco, and Carli (1988) demonstrated the effect of the parents' adjustment to the illness on rest of the family. In their sample of parents and children from 35 Italian families, the ill child's adjustment was correlated with the mother's adjustment and negatively correlated with both the mother's and father's perceived satisfaction with social support. Another study from Italy, this one qualitative, found that defense mechanisms which the family used to face the fear of death altered the family structure in ways which blocked the family's developmental cycle (Soccorsi, Rubbini Paglia, Lombardi, Riccardi, & Mastrangelo, 1988)

Family communication has been reported to be an important variable in the process of transition to the chronic illness experience. It seems to be an important mechanism by which the family is able to move from disequilibrium to reorganization (Kupst, Schulman, Maurer, Morgan, Honig, & Fochtman, 1984). Although communication is conceived of as a family style in which family members are free to bring up and discuss their concerns (Spinetta, 1978),

all of the studies reviewed measure content of communication rather than process (Birenbaum, 1987a, 1987b, 1989; Cohen, 1985; Spinetta & Deasy-Spinetta, 1981). Communication about the illness and its prognosis, measured as knowledge and participation in discussion by family members, is positively correlated with family adjustment in of these studies. Today most ill children and their siblings receive an explanation of the illness and the treatment plan. However, the degree to which continuing open communication about feelings and concerns occurs throughout the illness trajectory has not been measured. Whether pre–diagnosis communication patterns change or remain stable in the face of childhood cancer has not been investigated. The fact that much of this communication may occur in nonverbal channels (Watzlawick, Beavin, & Jackson, 1967) and is difficult to measure could account for the lack of study of this aspect of illness related family communication.

### Child's Response Over Time

#### Individual or Intrapsychic Aspects

As the child experiences the illness and treatment for some period of time, responses to the illness stabilize. Most children experience a period of remission, during which they continue to receive treatment, yet feel well and participate in school and play activities as they did prior to the illness (Koocher & O'Malley, 1981). Anxiety decreases as coping mechanisms become familiar and reliable . One study has found that the coping style preferred tends to be different over time (Smith, Ackerson & Blotcky, 1989) However, a higher level

of anxiety and preoccupation with threat to body integrity has been found for leukemic children when compared with other chronically ill children (Spinetta & Maloney, 1975; Spinetta, et al., 1973, 1974). One study suggests that although anxiety is greatest after diagnosis, among those who have been diagnosed for greater than 18 months, greater distress is associated with longer periods of time since diagnosis (Baider & De-Nour, 1989).

Powazek, et al. (1980) in a study of families one year after diagnosis, gathered data that lend support to the conceptualization of adjustment to diagnosis of childhood cancer as a transition, with disorganization followed by a reorganized and more stable period afterwards. In this study mothers reported that the patients had "quickly" returned to "their normal level of functioning".

Long term survivors (5 years since last evidence of disease) have been found to have scores within the normal range for psychological adjustment, although they did compare unfavorably with a matched group of children from the same hospital (Greenberg, Kazak, & Meadows, 1989). An Australian study which compared Child Behavior Checklist (CBCL) scores from teachers and parents, showed leukemic children to compare less favorably to control children chosen from their classes in school (Sawyer, Crettenden, & Toogood, 1986). In a follow-up study six to eight years after the diagnosis of leukemia, Kupst and Schulman (1988) found that 75% of the children were in school and were doing well, whereas the other 25% had poor grades or had had a learning disability diagnosed.

### Social Role Aspects

During the remission and maintenance treatment phase, children with cancer return to a stable, although different level of functioning in their social roles. Again, Powazek et al. (1980) reported that 86% of the children had returned to school within 6 months of diagnosis. However, in order to return to school, many children have had to make adjustments to repeated absences for clinic visits, hospitalizations or low white cell counts, sometimes resulting in difficulties in the classroom setting (Sawyer, et al., 1986).

Anecdotal reports of changing peer relationships and leisure activities also appear in the literature (Kagen–Goodheart, 1977). These changes may be related to the child's adjustment to fluctuating levels of energy, changed appearance and self-esteem, or to parental concern and overprotection. One child in remission wrote of feeling different. Part of this differentness from other children she attributed to visible physical differences. However part was attributed to her sense of being different because of the nature of the illness and it's existential challenge (Cunningham, 1983).

The ill child may also have arrived at different relationships with the siblings as a result of the family reorganization around the illness. Siblings and ill children have described themselves as closer together and also as having additional strains in their relationships. These ambivalent feelings sometimes occur simultaneously as the children respond to the illness (Kramer & Moore, 1983; Birenbaum, 1987a). While the siblings must adjust to a special

status given to the ill child (Birenbaum, 1987a), the ill child must contend with jealousy and anxiety on the part of siblings (Kagen–Goodheart, 1977).

### Parent's Response Over Time

#### Individual or Intrapsychic Aspects

One hallmark of the reorganization phase of the parents is the ability to articulate what the meaning of the illness experience of the child has for their lives. The level of sophistication varies widely, but most parents can identify some meaning of the illness for their lives. This meaning is reflected in the way that they have chosen to structure daily living patterns.

Anxiety has been noted to decrease for mothers (Magni, et al., 1983; Powazek, et al., 1980) and fathers (Magni, et al., 1983) during the remission phase of the illness. However, in both studies, the mothers reported a still higher level of anxiety than did mothers of healthy children. A longitudinal study of parents of children with cancer showed anxiety of both fathers and mothers to decrease from the time of diagnosis throughout the first year (Fife, et al., 1987). Of the fathers, 21.4% had scores elevated above the norm at three months post diagnosis, and 28.6% of mothers had elevated scores at three months post diagnosis. Kupst & Schulman (1988) also found an improvement in adjustment for both parents from 2 years after the diagnosis of leukemia to 6 years after diagnosis. Magni et al. (1983) found that despite improving scores on several measures of adjustment, 8 months post diagnosis and 20 months post diagnosis (Magni, Carli, et al., 1986) the parents of children with cancer showed subtle, yet persistent signs of depression. Another study (Wells et al.,

1989) showed that 69% of parents of children with cancer felt “under a strain”, 88% felt fatigued, 31% had difficulty sleeping and 38% had difficulty relaxing. However in this same study, 80% of parents reported that they felt hopeful. Hopefulness was also reported by a group formed for parents of children with cancer (Wells, Heiney, Cannon, Ettinger & Ettinger, 1987).

The pattern of decreased, yet still present signs of disruption seems to be generally true of the reorganization phase. Reorganization is accompanied by decreased perception of distress, but the continued threat of unknown outcome prohibits a return to pre-illness levels of functioning and experiencing (Koocher & O'Malley, 1981; Van Dongen-Melman & Sanders-Woudstra, 1986). For example, an increase in parental denial in the remission phase aids in the adaptation to daily living when the child feels well (Lansky, 1974; Friedman, 1967; Wells, et al., 1987). Self-esteem has also been shown to change for mothers and fathers (Cornman, 1988).

A report of the coping resources utilized by parents of adolescents included spending time away from the ill child, group meetings, talking with other parents, working with a counselor, and books (Wells, et al., 1989). There are not many other studies specifically reporting on coping resources and strategies utilized by parents as they reorganize family life after the diagnosis of childhood cancer.

### Social Role Aspects

Little has been researched about how roles change in the reorganization phase for the parents. It appears that most parents have established a pattern for



managing the additional role expectations placed on them by the child's illness. Clinical observation shows that most parents have mobilized social support resources in predictable patterns, assigned some of the tasks to other family members, or have resigned themselves to the overload that they experience.

It may be hypothesized that to some extent the roles of one or both parents must be reorganized to provide the ongoing medical treatment of the child. The degree to which parental roles reorganize around the child's illness seems to vary widely. Factors such as severity of symptoms and meaning of the illness for the parents influence how much their roles become invested in the child.

#### Sibling Response Over Time

Several studies have interviewed siblings to describe their reactions to childhood cancer. Iles (1979) interviewed 5 children with siblings in different stages of cancer treatment. Kramer (1984) interviewed 11 siblings of 9 children who had been diagnosed with leukemia for at least 6 months with no central nervous system involvement or relapse. Twenty open-ended and semi-structured questions were asked to arrive at the child's perception of changes within the family and emotional responses of the sibling to those changes. Koch-Hattem (1986) interviewed 32 siblings of children with cancer, using forced choice and open ended questions. Hanigan (1988) also interviewed siblings to determine their perceptions of living with a brother or sister with leukemia. Walker (1988) used a variety of projective techniques and semi-structured interviews as well as interviews with the parents to derive a taxonomy of sibling coping behaviors. This study suggested a complex and

profound response on the part of siblings to the diagnosis of childhood cancer as well as pioneering a combination of data collection techniques for getting rich data from and about children.

Change was a recurrent theme for siblings in the qualitative studies described above (Iles, 1979; Hanigan, 1988; Koch–Hattem, 1986; Walker, 1988). Change was categorized as loss (Iles, 1979) or negative change (Hanigan, 1988; Koch–Hattem, 1986) or as gains (Iles, 1979) or positive change (Hanigan, 1988). Negative changes or loss included interpersonal relationships, routine family life and the environment (Iles, 1979); affect including feeling bothered, sadness, scaredness and anger (Koch–Hattem, 1986); and isolation, fear, and helplessness, (Hanigan, 1988). Gains or positive change included empathy with parents, cognitive understanding, respect for the ill child (Iles, 1979); and self–pride, personal maturation and family cohesion (Hanigan, 1988). A confusing finding was the one study in which fewer than half of the siblings interviewed reported change (Koch–Hattem, 1986). The question is raised as to whether the siblings were using the same criteria for change as most researchers.

Additional themes identified in the sibling studies were loss and fear of death (Walker, 1988); and emotional realignment, separation, and the therapy regimen as sources of stress for the siblings (Kramer, 1984). Kramer reported emotional consequences of the stress, some of which were similar to the changes identified by the other authors. Positive consequences reported were increased sensitivity and empathy, personal maturation, increased family

cohesion, and sometimes a new protective role toward the ill child. Negative consequences included increased sibling rivalry, anger and frustration, rejection, guilt, lack of information, decreased involvement with parents and the ill child, witnessing the ill child's physical and personality changes and pain, loneliness, sadness, guilt, confusion, and anxiety.

Koch–Hattem (1986) and Walker (1988) described coping strategies utilized by the siblings. Those reported by Koch–Hattem included venting their feelings, turning to others for comfort, being alone, turning to security objects, giving attention to the ill child, suppressing expression of anger, and finding other things to do. Walker reported similar coping strategies which were categorized as cognitive (intrapsychic, interpersonal, and intellectual) and behavioral (self–focusing, distraction, and exclusion).

Like the qualitative studies above, at least one quantitative study has shown siblings to have difficulties with childhood cancer (Cornman, 1988). In contrast to that study and to the qualitative studies reviewed above, at least one quantitative study has found that the siblings do not show any more difficulties than a matched group of control children on parent CBCL scores (Sawyer, et al., 1986). However the authors explain that this is an instrument designed to detect pathological adjustment problems, and may not be sensitive enough to detect subtle differences between the two groups.

#### Family Unit Response Over Time

The family is able to reorganize in ways that aid in coping with the illness (Koch, 1985; Kupst & Schulman, 1988; Sawyer, et al., 1986; Spinetta &

Maloney, 1975). Siblings may form a closer, more cohesive, more self-sufficient subsystem, or a well sibling and one parent may develop a closer relationship (Birenbaum, personal communication, May 1987). Many families report after the disruption of the diagnosis period has subsided that the illness has brought them closer together.

Early studies report divorce and marital separation as a consequence of the family's reorganization around childhood cancer. However, in these studies, divorce rates are not compared with those of the general population (Binger et al., 1969; Kaplan, et al., 1976). More recent studies have shown a rate of divorce lower than that of the general population (Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980; Lansky, Cairns, Hassanein, Wehr, & Lowman, 1978). Parents of children with cancer do report a higher level of marital strain than the normal population, but something in the process of adjusting to the illness holds these families together (Cornman, 1988; Lansky, et al., 1978).

Reorganization of the family may be apparent in changed patterns of daily living (Kramer, 1984). Siblings report an increased responsibility for the monitoring or care of the ill child (Birenbaum, 1987a). Even the youngest children can articulate changes such as that their friends cannot come and play if the friend has a cold or if the ill child has a low white count (Birenbaum, 1987a).

A major component of the reorganization is the uncertain knowledge of the child's prognosis. The knowledge that the child could die sooner than normally expected is apparent in the family interactions, in their decisions, and in the

aura of mild anxiety that is frequently present. One study found significant differences between families with a child with cancer and comparison families on the intellectual and cultural orientation subscales of the Family Environment Scale, suggesting that in families of childhood cancer survivors there was less emphasis on these aspects of family life than in the comparison families (Greenberg, Kazak, & Meadows, 1989). The anxiety often alternates with denial of the potentially fatal outcome of the disease. Despite the threat of the "Sword of Damocles", many parents say of living with childhood cancer that it is "no big deal" or that they "get used to it".

One salient observation is that the manner in which families reorganize themselves may not be judged to be functional by the health care professional. A classic example is that many families allow the ill child to sleep with one or both parents, even into adolescence. Even though this is often viewed as abnormal, the meaning of this reorganizational tactic from a transition perspective could be considered in terms of the long term functioning of the particular family involved, before intervention is implemented.

As described above, families and their individual members experience disequilibrium and subsequent reorganization of individual and family structure and functioning when a child is diagnosed with cancer. This pattern is the same as that described for a generic transition and suggests that a transition perspective is a useful framework for nursing research and intervention with these families. Due to the exploratory nature of the hypotheses presented in this paper, it is premature to base nursing intervention on this conceptual framework

at this time. However, a transition framework does suggest some immediate research implications.

### Transitions

Transition as a perspective has been described and utilized by a variety of disciplines and sub-disciplines. This cross disciplinary influence is reflected in the diversity of definitions in the literature. Because transitions are described for individuals and families, both of these subconcepts will be considered. There is debate as to the scope of the concept, the nature of the transition process, the critical dimensions of a transition, the beginning and end points, and the outcome.

These differing viewpoints are presented by perspective in Table 1. Several aspects of the concept of transition came up repeatedly in the literature. These aspects are teased out along the vertical axis of Table 1 and are labeled Scope, Beginning Point, Process, End Point, Outcome, Exclusions, and Research. The perspectives reviewed include: Psychological, including psychiatry, social work, and counseling; Role Theory; Developmental/Life– Span; Nursing; Person– Environment Fit; and Humanistic/Existentialist.

An individual transition can be thought of as the process of moving from one relatively stable state of organization to a different stable state of organization. Transitions may be self–initiated or forced upon the individual by situational circumstances beyond the individual's control. Transitions are characterized by disorganization and upheaval during the process of movement toward the stable state. In addition to the process, the concept of transition

**Table 1.**  
Transition Concept Delineation by Perspective

Concept	Psychological	Role Theory	Developmental/Life-Span
<b>Scope</b>	<p>Any change of life space. However, psychosocial transitions are the only major transitions requiring study and intervention (Parkes, 1971). Any change requiring reorganization of emotional life and relational arrangements (Weiss, 1976).</p> <p>Tends to be broad, including any stressor which requires a coping response (Schlossberg, 1984).</p>	<p>Limited to changes in role expectation.</p>	<p>Developmental transitions and transitions which a large percent of the population experiences in the course of maturation (Lowenthal et al., 1975).</p> <p>Use terms "transformations", "change in ongoing life pattern", "transitions" interchangeably with no definitions (Hultsch &amp; Plemons, 1979).</p>
<b>Beginning Point</b>	<p>Major change in life space which is lasting in its effects, takes place over a relatively short period of time and affects large areas of the assumptive world (Parkes, 1971).</p> <p>Disequilibrating event or series of events (Silverman, 1982).</p>	<p>Strain between old and new role expectations, perceived by the individual as an intrapsychic state of arousal, excitement or irritation (Allen &amp; van de Vliert, 1984).</p>	<p>Stressful life events, a stressful experience involving pain or requiring a role transformation. Individual events (happen to everyone in the course of the life cycle) or cultural events (major catastrophes affecting large numbers of people such as an earthquake) (Hultsch &amp; Plemons, 1979).</p> <p>Other developmental models view the beginning as intrinsic to the individual, a prepatterned developmental occurrence which is different for each individual, but universal (George, 1982; Levinson, 1978).</p>

Table Continued

Table 1 (cont'd)

Concept	Psychological	Role Theory	Developmental/Life Span
<b>End Point</b>	Establishment of a new stable life with a new stable identity (Weiss, 1976).		
<b>Outcome</b>	Possibly adequate or deficient for meeting new demands (Weiss, 1976). Adaptation: mastery, coping, and defense (Golan, 1981).	Reduction, increase or unchanged level of experienced strain. A gradual change in self-identity (Allen & van de Vliert, 1984).	Developmental progress or failure is possible. Failure to successfully negotiate one transition is believed to cause difficulty in future responses to transitions (George, 1982).
<b>Exclusions</b>	Maturation or gradual change processes; frightening situations or transient illness which cause no long term change in the assumptive world; lifelong states of deprivation, deformity or stigma. Every stressful event does not cause a transition, only those causing cognitive restructuring of the world are considered transitions (Parkes, 1971). A transition may make a person vulnerable to illness (Parkes, 1971).	Does not view subjective experience or interpretation as influencing transitions. Precludes changes other than social role changes as triggers of a transition (George, 1982).	
<b>Research</b>	Clinical or program evaluation	Cross-sectional	Longitudinal, multivariate, quantitative (Hultsch & Plemons, 1979). Qualitative, phenomena will not be revealed by the study of concrete variables or events, but rather the lived life as it evolves (Levinson, et al., 1978).

Table Continued



**Table 1 (cont'd).**  
 Transition Concept Delineation by Perspective

Concept	Nursing	Person Environment Fit	Humanistic Psychology
<b>Scope</b>	Includes both process and outcome of complex person-environment interactions (Chick & Meleis, 1986).	Changes where perturbation to the person-in-environment system is experienced as so potent that ongoing modes of transaction with the physical, interpersonal and socio-cultural features of environment no longer suffice (Wapner, 1981).	
<b>Beginning Point</b>	May be intrinsic to individual (as a developmental transition) or social, cultural, or environmental events may trigger the transition (Chick & Meleis, 1986).	Change in person or environment or both (Wapner, 1981).	An ending of an old situation (Bridges, 1980).

Table Continued

Table 1 (cont'd)

Concept	Psychological	Role Theory	Developmental/Life-Span
Process	<p>Restructuring of ways of looking at the world and plans for living in it (Parkes, 1971). Reorganization of emotional life and other relational arrangements (Weiss, 1976).</p> <p>Role change taking place over time; impact, recoil, and accommodation phases (Silverman, 1982).</p> <p>Instrumental tasks and psychosocial or affective tasks--a problem solving approach to moving through the transition (Golan, 1981).</p>	<p>Reaction to strain, which consists of cognitive, affective and behavioral responses. Involves moving across role positions or changing behaviors associated with a continuously occupied position (Allen &amp; van de Vliert, 1984). Three important variables to consider are anticipatory socialization, transition procedure, and amount of normative change. Not always fraught with turmoil (Burr, 1972).</p>	<p>A shift from one life structure to another, terminating the existing one and creating the possibility for a new one. Involves an ending, a process of separation or loss (Levinson, et al., 1978).</p> <p>Often conceptualized in terms of what variables affect outcomes such as gender, religion, timing of events, personality variables, etc. (for example Hultsch &amp; Plemons, 1979). Initial appraisal, selection of coping strategies (Hultsch &amp; Plemons, 1979).</p> <p>A basic change in the fabric of one's life which occurs over time; work of eras and provides continuity between them. Creation of a boundary zone which terminates one era and initiates a new one. On an intrapsychic level, neglected parts of the self more urgently seek expression and stimulate the modification of the existing structure (Levinson et al., 1978).</p>
			<p>There is disagreement as to whether the transition process is experienced as a crisis or not (George, 1982).</p>

Table Continued

**Table 1 (cont'd)**

Concept	Nursing	Person Environment Fit	Humanistic Psychology
Process	<p>Disconnectedness associated with disruption of the linkages on which the person's feelings of security depend. Patterns of response such as disorientation, distress, irritability, anxiety, depression, changes in self-concept, changes in role performance and others (Chick &amp; Meleis, 1986).</p>	<p>Disruption of self-world relations and attempts to re-establish equilibrium between self and non-self. Action regulated by symbolic values and norms in the environment and the relations among them take on different saliences and experiential relevance. The individual utilizes various strategies and may temporarily regress psychologically (Wapner, et al., 1981).</p>	<p>Natural process of disorientation and reorientation that marks turning points of the path of growth. A period of confusion and distress. Letting go of an old situation, suffering the confusing nowhere of in-betweenness, and launching forth again in a new situation. Disorientation defined as a shift in sense of time and space; a confusion and emptiness; sense that ordinary things have an unreal quality about them. A shift in values. A neutral zone experience of withdrawing to regroup may or may not be experienced as part of the transition (Bridges, 1980).</p>

Table Continued

Table 1 (cont'd)

Concept	Psychological	Role Theory	Developmental/Life Span
<b>End Point</b>	Establishment of a new stable life with a new stable identity (Weiss, 1976).		
<b>Outcome</b>	Possibly adequate or deficient for meeting new demands (Weiss, 1976). Adaptation: mastery, coping, and defense (Golan, 1981).	Reduction, increase or unchanged level of experienced strain. A gradual change in self-identity (Allen & van de Vliert, 1984).	Developmental progress or failure is possible. Failure to successfully negotiate one transition is believed to cause difficulty in future responses to transitions (George, 1982).
<b>Exclusions</b>	Maturation or gradual change processes; frightening situations or transient illness which cause no long term change in the assumptive world; lifelong states of deprivation, deformity or stigma. Every stressful event does not cause a transition, only those causing cognitive restructuring of the world are considered transitions (Parkes, 1971). A transition may make a person vulnerable to illness (Parkes, 1971).	Does not view subjective experience or interpretation as influencing transitions. Precludes changes other than social role changes as triggers of a transition (George, 1982).	
<b>Research</b>	Clinical or program evaluation	Cross-sectional	Longitudinal, multivariate, quantitative (Hultsch & Plemons, 1979). Qualitative, phenomena will not be revealed by the study of concrete variables or events, but rather the lived life as it evolves (Levinson, et al., 1978).

Table Continued

Table 1 (cont'd)

Concept	Nursing	Person Environment Fit	Humanistic Psychology
<b>Endpoint</b>		Re-establishment of a self-world harmony which allows for autonomous functioning of the individual (Wapner, et al., 1981)	
<b>Outcome</b>	A period of greater stability relative to what has gone before (Chick & Meleis, 1986).	Regressive change or progressive development or both (Wapner, 1981).	A new beginning. (Bridges, 1980).
<b>Exclusions</b>	Change which the individual does not recognize as disruptive and requiring new responses (Chick & Meleis, 1986).		
<b>Research</b>	No generalizations possible	No generalizations possible	No generalizations possible

encompasses the individual's response to the disruption experienced (Chick & Meleis, 1986). Several authors have stressed that the individual must be aware of the transition or change process in order to be going through a transition (Chick & Meleis, 1986; Schlossberg, 1984). Chick & Meleis (1986) further state that a person's response to the transition is influenced by how he/she perceives the transition, the meaning it has and the expected outcomes of the transition.

The starting point of a transition is an event or situation requiring a process of change (Parkes, 1971). This process has been described as a restructuring of the cognitive framework and the relational patterns that organize the individual's daily life (Parkes, 1971; Weiss, 1976). Clinicians tend to discuss the transition process in terms of coping strategies or tasks (Golan, 1981; Schlossberg, 1984). The transition ends with a new stable state (Chick & Meleis, 1986; Parkes, 1971; Weiss, 1976). This has been referred to as "adaptation" (Schlossberg, 1984). However, this term connotes a static state, so some authors prefer the term "response to transition" (Hopson, 1977) which connotes a more dynamic state with the capacity for positive or negative change.

A transition is often associated with a positive direction of movement, such as a higher level of organization, more maturity, or a greater level of development. However, transitions are not necessarily limited to such forward progression. The transition may result in regressive change, progressive development or both simultaneously (Schlossberg, 1984; Wapner, 1981). The

possibility exists also for change that is merely different, i.e., neither regressive nor progressive.

The literature discusses several critical dimensions on which transitions may be categorized: developmental versus situational, normative versus non-normative, anticipated versus unanticipated, voluntary versus involuntary (Chick & Meleis, 1986), clear entry and exit versus ambiguous entry and exit (Chick & Meleis, 1986; Glaser & Strauss, 1971), and agent as locus of change versus setting as locus of change (Wapner, 1981). Where the transition lies between the poles along each of these dimensions influences the nature of the transition process for the individual.

Schlossberg (1984) specifies three dimensions as critical for determining the appropriate intervention: type of transition, context of transition, and impact of the transition on the individual. Type of transition is divided into four categories: anticipated, unanticipated, chronic hassles (Lazarus, 1981), and nonevent. This conceptualization of type of transition differs from the dichotomous dimensions described by Chick and Meleis (1986). Schlossberg equates hassles and non-events with the anticipated–nonanticipated dimension, which seems to be an oversimplified equation of two qualitatively different aspects of a transition. The categories are not mutually exclusive, thus diminishing their usefulness for diagnosis and intervention. This conception of transition contrasts with the psychiatric perspective which states that all stressful situations do not create transitions. The equation of daily hassles with transitions makes the concept quite broad, and does not allow for

discrimination of persons in transition from those not in transition, as almost all persons have their share of daily hassles.

Agent versus setting as focus of change is another critical dimension of transitions for those using the person–environment fit perspective. Setting as focus of change is defined as changes in the physical setting (such as earthquakes, relocating) or changes in the socio-cultural environment (such as into or out of an institution). Changes in agent refer to changes in role or status or physical well-being of the individual. Whether agent or setting is the focus of change contributes to the experience of the transition. When one is designated as the focus of change, the other pole is involved, but only in a minor fashion (Wapner, 1981).

Role theorists (Allen & van de Vliert, 1984; Burr, 1972) view characteristics of role relationships as the critical variables determining the transition process. These important variables include amount of anticipatory socialization, role clarity of new and old roles, role conflict, role strain, role incompatibility, degree to which roles are compartmentalized, amount of normatively prescribed activity, degree to which roles facilitate goal attainment, value of goals, length of time in a role, importance and/or definiteness of the transition procedure, and the amount of normative change involved in the transition. This role theory formulation of the transition construct does not allow for the influence of subjective experience on the transition and seems to be more comprehensive when combined with a transition model with an interpretative component (George, 1982).



The transition concept must be differentiated from similar concepts, most specifically crisis and change. Where these concepts overlap, a case must be made for the advantages of intervening from a transitions perspective rather than using crisis or change theory to guide practice. Transition is a response to disrupting events, whereas, change may be the disrupting event itself, and does not involve the response aspect (Chick & Meleis, 1986).

Crisis theory is similar to the transition construct, however, there are some differences. Many crises may be described as transitions. However not all crises are transitions, as a crisis allows for the return of the individual to his/her previous level of functioning (Aguilera & Messick, 1982; Clements, 1983). Furthermore, a crisis is defined as a situation demanding resources that the individual does not have (Clements, 1983). Transitions do not necessarily demand resources the individual does not have. Rather a transition demands that the individual reorganize and restructure his/her world. This transition process may require resources the individual does not possess, but it may also involve reorganization of existing resources.

Most authors do not define family transitions as such. Rapoport (1963) is the exception, and refers to points of no return that promote disequilibrium in both individual and family transitions. However, many authors discuss the effect of an individual's transition on the family (Golan, 1981; Parkes, 1971). The implication is that the family unit itself has also undergone a transition or restructuring. Others describe group transitions as a transition involving more than one person (Benoliel, cited in Chick & Meleis, 1986), as in transitions

experienced by a family when a crisis event occurs that affects all family members. How this family transition differs from a collection of simultaneous individual transitions is not clear.

Some authors have mentioned particular characteristics of a family transition (for example, Allen & van de Vliert, 1984; Chick & Meleis, 1986; Rapoport, 1963). These characteristics include: shifts in roles for individual family members (Allen & van de Vliert, 1984); reallocation of roles among family members (Allen & van de Vliert, 1984); changes in general family affect (Rapoport, 1963); and changes in family functions receiving emphasis or accomplished within the family (Rapoport, 1963).

The context embeddedness of a transition makes the consideration of transitions within families complex. Because individual transitions may be simultaneous and competing or overlapping, a given individual's transition may or may not cause a reorganization of the family.

#### Transition as a Nursing Phenomenon

Chick & Meleis (1986) present an argument on the usefulness of transition as a concept for nursing, asserting that it is one of several concepts that will be required to supplement the three central concepts of human beings, environment and health. Transition is a key concept for nursing because it will aid in interpreting person–environment interactions in terms of their actual and potential effects on health (Chick & Meleis, 1986, p. 239). Nursing practice stands to gain from conceptualization of transition in all its variations.

Review and comparison of nursing theories with the concept of transition shows most prominent theories to be compatible, and even interdependent with transitions (Chick & Meleis, 1986). This is due to nursing's focus on human responses to health problems that usually involve change and instability. Many nursing interventions are dependent upon initiating changes in the person–environment relationship.

Nursing therapeutics can be considered in their relationship to transitions experienced by the client, with new insight gained into effectiveness. Transition provides a time and process oriented context to view nursing situations as well as client responses to nursing interventions. The concept of transition brings into focus the "at risk" status that individuals experience as a result of events that are not directly health related, thereby highlighting the vulnerability of the client. The concept highlights for the practitioner the personal and social transitions the client is experiencing that may affect response to health related interventions (Chick & Meleis, 1986). A transition perspective permits viewing the client in a manner that is continuous over time and across dimensions of the client's life. Finally, from a transition perspective the practitioner can shift between outcome and process in designing and evaluating interventions.

For a practice discipline such as nursing, useful concepts must be applicable in the clinical setting. Reports of the use of the concept of transition in clinical practice are limited. However transition theory has received more attention in recent years, and has been identified as an important concept for development in nursing (Chick & Meleis, 1986).

One example of the use of the transition concept in clinical practice is the transitions services offered to families of persons who are dying (Tornberg, McGrath & Benoliel, 1984). These services have been described as "designed to offer personalized services and continuity of care to patients and families living with changing demands of progressive deteriorating illness" (Tornberg, et al., 1984, p.131).

Transition to home after bone marrow transplant for families of children has been described as an area for intervention (Freund & Siegel, 1986). Freund and Siegel (1986) conceive of any mental health professional, including mental health nurse specialists, as intervening with the family regarding the transition from bone marrow unit to home.

Most clinician–authors discuss interventions for individuals undergoing transitions. These interventions may be derived from theory or from trials in clinical practice. No interventions reported in the literature have been evaluated with rigorous experimental methods or controlled clinical trials.

Some frequently cited words of wisdom about intervention are that people who have come through transitions are the best helpers (Parkes, 1971; Silverman, 1982). This concept is often put into practice in the form of support groups of people who have experienced a similar situation and who then visit, counsel or serve as supports for others currently going through the transition. Silverman (1982) cites evidence that the shift in role to that of helper is beneficial in the response to transition of the one coming out of the transition period. Weiss (1976) describes the effect of these groups as providing an

"assured place in a temporary community" (p. 218). Support from others in general, such as good listening and mere presence, is also recommended (Silverman, 1982; Weiss, 1976).

Anticipatory socialization and information in the form of orientation and guidance are recommended by some researchers (Allen & van de Vliert, 1984; Parkes 1971; Silverman, 1982; Weiss, 1976). This includes cognitive material to help structure meaning, practical advice about how others have managed, specific skills, and discussion of risks and benefits of various strategies. A role theory perspective recommends formal or informal training for enactment of new roles (Allen & van de Vliert, 1984).

Weiss (1976) specifies that specific interventions need to differ according to content and context of the transition. Developing the particular format and content mix that will be effective for a particular transition will be a trial and error process. He further specifies that three kinds of helpers are needed: experts (professionals), veterans of the transition, and fellow participants in the transition.

Some authors have developed sequences of interventions that parallel phases or components of the transition process (e.g. Silverman, 1982; van de Vliert & Allen, 1984). Van de Vliert and Allen (1984) suggest interventions targeted at components of the role transition. The interventions begin with changing antecedent conditions and continue with facilitating role transition, reducing role strain, and altering reactions. They conclude with optimizing consequences. Each area for intervention is composed of strategies that

individuals engage in as well as interventions which the professional helper can prescribe for the client who seeks advice.

#### Summary

Conceptualization of family response to the diagnosis of childhood cancer as a transition is based on a synthesis of research findings in the area. The synthesis of diverse research findings is necessitated by the fact that the majority of research studies are lacking in a comprehensive conceptualization and focus. The synthesis is weakened by the differences in methods, measurement, and samples that can not be adequately adjusted for in making comparisons and contrasts.

Many studies have been conceptualized from a medical/psychological model (e.g., Binger, et al., 1969; Chodhoff, et al., 1964; Cohen, 1985; Fife et al., 1987; Geist, 1979; Green & Solnit, 1964; Lavigne & Ryan, 1979; Maguire, 1983; Powazek, et al., 1980; Spinetta, 1977; Tietz, et al., 1977; Wasserman, Thompson, Wilimas, & Fairclough, 1987) focusing on variables related to presence or absence of pathology (Spinetta, et al., 1982). The individuals involved in the transition have not had the chance to identify the issues and variables that are most salient to them.

Although there have been some quantitative studies with fairly sophisticated statistical analyses (Fife, et al., 1987; Spinetta, et al., 1981), initial conceptualization of family response and the multiple independent, intervening and dependent variables is lacking. There are no known published models that include a significant portion of the variables that have been studied in

relationship to family response to the diagnosis of childhood cancer. This lack of conceptualization indicates that additional descriptive investigation of the family response to the diagnosis of childhood cancer is needed.

Few studies have attempted to measure the complex interactions or communications within the family. Most of these studies have simplified the multiple dynamic interactions. Some examine only dyadic interaction (Cohen, 1985; Spinetta, et al., 1981). Often only one individual reports on the communication process of multiple individuals, providing only one view point (Cohen, 1985). Others investigate isolated aspects of communication such as content of verbal communication on certain topics, overlooking non-verbal communication (Cohen, 1985; Spinetta, et al., 1981).

Birenbaum (1987a), alone among investigators, collected data from all family members over age 5. However this study focussed solely on family communication. While Birenbaum's study contributes in a unique way to the communication process in families, it does not include as its focus the entire transition process which may be greater than family communication. In addition, this study provides retrospective data about the period immediately following the diagnosis, suggesting a need for prospective data from this phase of the trajectory. Therefore, data from Birenbaum's study, while supporting the idea that these families are experiencing a transition, does not provide a comprehensive picture of the experience of the family's response to the diagnosis of childhood cancer.

Only one study (Fife, et al., 1987) controlled for differences in prognosis when analyzing responses of family members to diagnosis of childhood cancer. Recent improvements in treatment have resulted in a variety of possible illness courses (Young, Ries, Silverberg, Horm, & Miller, 1986). Some children experience a rapid downward trajectory, while others experience an extended chronic illness phase with a terminal event and still others experience a chronic illness phase followed by long term disease free survival and "cure". The differences created in meaning of illness and expected outcome are hypothesized to affect the family's response to the illness. However, most studies continue to treat all trajectories as homogeneous obscuring a possible cause of variation in family response.

The gaps in the knowledge of family response to childhood cancer seem to be centered on the lack of complete conceptualization of a complex, dynamic, interactive family process. Further, the family response is not viewed from a transition perspective in any study. Finally, there is a lack of prospective data about the change and disruption experienced by the family.

The present study addressed these gaps by allowing all family members to describe interactions related to the diagnosis of childhood cancer. The assumption of a symbolic interactionism paradigm defined the important variable for study to be the process by which the family creates, restructures, and transmits meaning related to the illness experience. Symbolic interaction values the contributions of all actors in the interaction process, and therefore allows for consideration of the points of view of all family members, as well as



the process that occurs between them. Because symbolic interaction is a process oriented paradigm, it is compatible with study of a process concept such as transition and suggests a qualitative method and grounded theory analytic technique (Blumer, 1969; Glaser & Strauss, 1967).

## METHODS

This was a descriptive study of the experience of families in which a child is diagnosed with cancer with a favorable prognosis. For the purposes of this study, cancer with a favorable prognosis was considered to be any subtype of cancer for which the expected 5 year survival rate is 60% or greater. The major research question was as follows: What is the process families move through in adapting to the diagnosis of cancer with a favorable prognosis in one of the children? The study examined multiple interactions within the family, as well as the experience of individual family members. The method, a modified grounded theory approach, was derived from symbolic interaction. Symbolic interaction is a theoretical perspective which is particularly interested in the meaning of experiences and the processes by which those meanings are derived. Data collection was prospective because time may change the memories people have of their perception of events.

### Assumptions

One major assumption underlying the conceptualization of family transitions was that families are social systems (Broderick & Smith, 1979) with the following characteristics of systems: holism, dynamism, growth in time, centralization, differentiation, and competition (Polkinghorne, 1983). In addition, systems fall on a continuum with open systems anchoring one end and closed systems the other (Polkinghorne, 1983). A family system, since it is a living system, is never completely closed.

It was further assumed that the investigator did not need to possess a "tabla raza" with respect to the focus of this study. Although many grounded theorists recommend that the investigator approach the field without prior exposure to the literature or the problem being studied, this recommendation has been violated in many well accepted previous studies (e.g., Quint, 1969). Further, due to the nature of clinical practice and educational preparation for study in the area, it is nearly impossible for a clinical researcher to arrive at a research question or problem to be focussed on without prior exposure to the problem as it occurs in clinical practice and as it has been discussed in the literature. Rather, the task for the researcher is to be explicit about assumptions and expectations prior to implementation of the study (Hutchinson, 1986).

#### Design

The design of this study was descriptive and prospective. Intensive interviewing of family members was the principal data collection method. Qualitative analysis, similar to the grounded theory method described by Glaser and Strauss (1967), and as utilized by Quint (1969), was the analytic strategy. This strategy was chosen because its aim is "the discovery and conceptualization of the essence of complex interactional processes" (Hutchinson, 1986, p.112) which was the focus of this study.

#### Setting

Informant families were referred to the study by pediatric oncologists in the pediatric clinic at a health sciences university in the Pacific Northwest. This clinic is a Children's Cancer Study Group (CCSG) site. Children are referred to

the clinic from throughout the region. Services include pediatric radiation therapy, pediatric surgery, and treatment by the pediatric oncologists and the nurses in the pediatric clinic. One nurse works exclusively with the cancer patients, with assistance from other nurses in the clinic. When the children are hospitalized, they are on one of two pediatric units of the hospital. A child life therapist is available on the inpatient unit, but not in the outpatient clinic. Social services are available by physician or nurse referral, but are not routinely ordered.

### Sample

The population sampled in this study was all families with children diagnosed with cancer with a favorable prognosis. In addition families met the following criteria: at least one child in the family was 5 years or older; the ill child did not have another chronic illness, including but not limited to, Down's Syndrome, Fanconi's Anemia, neurofibromatosis, and Ataxia telangiectasia; and the family was living within moderate driving distance of the university (approximately 200 miles). Each family identified as meeting the criteria was approached and asked to participate. The families constituted a convenience sample. Initially, it was not required that all families speak English. However, after interviewing one family in which the parents did not speak English, it was decided to add an additional criterion, due to the difficulty in understanding the subtle nuances of a language in which the researcher was not fluent. This family was included in the study because although the data were not as detailed, the experiences of this family were consistent with the experiences of

the other families in this study. The data from this family are not as extensive as those from other families; it is not known whether the lack of detail is idiosyncratic to this family or due to the language differences between researcher and informants.

Four families refused to participate. In two of those families, the stress of the treatment combined with other stressful family events were cited as factors precluding their participation. In the two remaining families, the fathers both stated that their families did not want to rehash all of “those negative emotional things” and did not want to share them with a stranger. These families may have been different in their perceptions of the illness experience and in the way in which they responded to the illness. Their non-participation may have limited the variation of responses and therefore the transition model derived in this study. One additional family which met the criteria was diagnosed and discharged home to the local physician for care while the researcher was on vacation. It was decided not to pursue this family via long distance telephone, in part because it was past the specified timeline for the first interview. A demographic description of the sample appears in Tables 2–6.

The study sample consisted of 7 families, 6 caucasian and 1 Hispanic. Two families identified themselves as Roman Catholic, the others as Protestant. All of the fathers were working full time. Prior to diagnosis, four of the mothers were working full time and three part time. Of those 3 quit their jobs at least temporarily at the time of diagnosis. After diagnosis, 3 of mothers were working

**Table 2.** Characteristics of the Families (n = 7).

	Number	Percent
Number of People in Family <sup>a</sup>		
4	1	14
5	3	43
7	3	43
Total Family Income <sup>b</sup>		
\$5,000–15,000	3	43
\$15,001–25,000	2	29
\$25,001–35,000	1	14
\$45,001–55,000	1	14
Ethnic Background		
Caucasian	6	85
Hispanic	1	14
Religion		
Protestant	5	71
Catholic	2	29

**Note.** Some percentages don't add up to 100% due to rounding.

<sup>a</sup> Mean = 5.7.

<sup>b</sup> Median = \$17,501; Mode is \$5,001–15,000.

**Table 3.** Characteristics of the Fathers (n = 7).

	Number	Percent
<b>Education</b>		
None	1	14
High School Diploma <sup>a</sup>	4	57
Some College or Higher	2	29
<b>Occupation</b>		
Blue Collar (manual labor)	4	57
White Collar (clerical, business)	1	14
Professional (teacher, academic,clergy)	2	29

<sup>a</sup> Includes GED

**Table 4.** Characteristics of the Mothers (n = 7).

	Number	Percent
<b>Education</b>		
Grade School	1	14
High School Diploma <sup>a</sup>	3	43
Some College or Higher	3	43
<b>Occupation</b>		
Blue Collar (manual labor)	3	43
White Collar (clerical, business)	3	43
Professional (teacher, academic,clergy)	1	14
<b>Employment Status</b>		
Working pre–diagnosis	6	85
Quit at diagnosis	3	43
Start/return post diagnosis	4	57

<sup>a</sup> Includes GED

**Table 5.** Characteristics of the Ill Children (n = 7).

	Number	Percent
Diagnosis (Long Term Survival) <sup>a</sup>		
Acute Lymphocytic Leukemia (80–90%/5yr)	3	43
Non Hodgkins Lymphoma–Localized (95%)	3	43
Lymphoblastic Lymphoma Stage IIIB (75%)	1	14
Age at Diagnosis (years) <sup>b</sup>		
2	1	14
5	1	14
6	1	14
7	2	29
8	1	14
10	1	14
Gender		
Male	3	43
Female	4	57
Position in Family		
Oldest	1	14
Middle	2	29
Youngest	4	57

<sup>a</sup> Survival rates quoted to the families

<sup>b</sup> Mean = 6.4



**Table 6.** Characteristics of the Siblings (n = 19).

	Number	Percent
Age at Diagnosis		
< 1 year	1	5
Preschool (1–5 years)	6	31
School Age (6–12 years)	7	36
Early Adolescence (13–16 years)	3	16
Late Adolescence/Early Adulthood (17–21 years)	2	11
Gender		
Male	10	53
Female	9	47

full time, 2 were working part time and 1 mother had returned to her career as had been planned.

This sample differs in many ways from national averages. The families in this sample (mean number of family members was 5.7) were larger than the national average of 4.14 for married couples with children, and the family income (median \$17,501; mode less than \$15,000) tended to be lower than the national median of \$40,352 for two earner families (U.S. Bureau of the Census, 1989). All of the families were two earner families either before or after the child was diagnosed. Parents' educational levels varied from none to graduate school. Eighty-six percent of the mothers and the fathers had finished high school or better.

The sample of ill children was compared with other samples of children with cancer. In the study sample a majority of ill children were girls (57%); national statistics indicate that cancer occurs more frequently in boys (Neglia & Robison, 1988; Sutow, 1984). The age distribution of the sample is not different from the national distribution of leukemia, which shows the peak incidence at ages 3–5 and gradually declining with increased age. The sample age distribution for lymphoma in the sample matches the peak incidence of the national age distribution of lymphomas (Sutow, 1984). The fact that there are no ill adolescents in the sample may be a reflection of the types and prognosis of cancer common in these age groups. Not having ill adolescents in the study may have altered the issues brought up by the families, as there may be some

issues related to the illness which are specific to the developmental phase of adolescence.

The majority of ill children in the sample were youngest in the family (57%). Siblings ranged in age from less than a year to 21 years (mean = 8.16 years). There was a slight predominance of brothers (53%) over sisters. All of the siblings in this study were living in the home, and all were biological siblings.

For this study it was decided to limit the focus to children with favorable prognosis cancer who experienced remission. Swenson and Stewart (1987) describe the variations in the course of illness dependent on such variables as stage of cancer at diagnosis, favorableness of the prognosis of the subtype, treatment protocol, and complications of treatment.

The present study held constant the variables of prognosis and remission as a part of the illness trajectory. This was done because Fife, et al. (1987) have analyzed data regarding family adaptation to the illness by groups based on prognosis. Although there were no significant differences between groups, the design reflects the assumption that prognosis (hence differing illness trajectories) does affect family adaptation. Small cell sizes may have precluded the significance of differences in Fife et al.'s (1987) study so that it seems wise not to abandon this assumption.

Diagnoses deemed to have a favorable prognosis were chosen primarily on the basis of statistics reported in CCSG's treatment protocols. This source was chosen because the physicians at the study site use these treatment protocols,

the physicians and parents have access to these data, and presumably treatment outcomes are similar to those reported by the CCSG. Table 7 lists the 11 favorable prognosis diagnoses which were acceptable for this study and their survival rates. A five-year disease free survival rate was chosen as the criterion where data were available. For some types of cancer these data were not available, so statistics from the nearest time period were used. For example, disease free survival rates for rhabdomyosarcoma were quoted for three years after diagnosis, but not for five years after diagnosis. In the case of any diagnosis for which it was questionable whether the prognosis was favorable or not, it was decided to exclude the diagnosis rather than include a diagnosis for which the prognosis might not be considered favorable. This conservative approach was chosen to ensure that the sample included only those children with a prognosis that was clearly favorable.

The sample focused on two distinct cancer trajectories. Children with both solid tumors and hematologic cancers were included. Solid tumors are associated with a quicker, surgically induced remission at the time of diagnosis. In contrast, remissions from leukemias and disseminated lymphomas are induced by chemotherapy or radiation 2-6 weeks after diagnosis. Final prognosis was similar for both groups.

Several chronic conditions, birth defects, and hereditary syndromes are associated with an increased incidence of leukemia and other cancers. Children who are diagnosed with cancer in addition to one of these conditions were excluded from the study, to prevent confounded responses to the other

**Table 7.**  
Favorable Prognosis Cancer Diagnoses and Disease Free Survival Rates.

<b>Diagnosis</b>	<b>Subtype/Stage</b>	<b>Disease Free Survival</b>	<b>Source</b>
Acute Lymphocytic Leukemia	Good Prognosis	80-90% (5 yr)	Children's Cancer Study Group-- Protocol CCG 104 8/30/82
	Intermediate Prognosis	60-70% (5 yr)	
Wilms Tumor	Favorable Histology	88% (2 yr)	National Wilm's Tumor Study Protocol CCG 461 6/9/87
Non Hodgkin's Lymphoma	Localized Disease	81% (3 yr)	Children's Cancer Study Group-- Protocol CCG 501 5-10-84
	Disseminated lymphoblastic	74% (30 mon) 70% (2 yr)	Wilson et al., 1984; Jenkin et al., 1984 Children's Cancer Study Group-- Protocol CCG 502 5-31-84
Hodgkin's Disease	All Types	Projected 75-80%	Children's Cancer Study Group-- Protocol CCG 521
Rhabdomyosarcoma	Group 1 and Group 2	>80%	National Cancer Institute Protocol-- Intergr-0032 Children's Cancer Study Group-- Protocol CCG 631 1984
Neuroblastoma	Stages I and II	63% (2 yr)	Lopez-Ibor & Schwartz, 1985
Retinoblastoma	All Stages	83-100%	Tapley, et al., 1984

condition with responses to the diagnosis of childhood cancer. These conditions included, but were not limited to, Down's Syndrome, Fanconi's Anemia, neurofibromatosis, Ataxia telangiectasia (Strong, 1984), and Drasch Syndrome. Second cancers which were diagnosed in a child were excluded for the same reason.

### Interview

Intensive interviewing is an emergent process in that specific content of the interview is decided upon by the informant and the interviewer as the interview proceeds. Subsequent interviews were then shaped to some extent by the content of the preceding interview, although always there was flexibility to follow the informant's lead in exploring new aspects of the topics specified a priori by the researcher as being of central interest, as well as allowing the informant to bring up new topics.

The interviews were semi-structured, with only a few broad questions mapped out ahead of the interview. Probes were used to help the informant to expand upon the responses and reflect on the meaning of the responses. As specific probes were found to be successful in eliciting information they were added to the structure of the interview. In addition, as preliminary analysis of the data was carried out, new probes were also added to the structure for the purpose of validating new information given by other informants. The interview schedules are shown in Appendix A. The questions in the schedule were elaborated further with probes to follow topics brought up by the individual

informant or topics brought up previously by other informants. Interview questions were reworded for children to reflect their developmental level.

In order to look at process over time, three segments of the life experience of the family were chosen as representative of the ongoing process of transition to the diagnosis of childhood cancer. These points in time were the first week after diagnosis, the first week after remission, and three months after remission. Remission was considered to be the medically defined condition of having no physical evidence of cancer. Remission and diagnosis were verified by the primary physician of the ill child or the medical chart.

In instances when diagnosis and remission occurred within 5 days of each other, the first and second interviews were combined. It was anticipated that data from these families would be different from families who had the two interviews separated, in that they would be dealing with the meaning of two phenomena simultaneously, rather than at two separated points in time. It was expected that families who experienced the separate occurrence of diagnosis and remission would have a more developed meaning of the illness at the second interview, than would families experiencing an instantaneous remission. The interview explored the effect of knowing that the child was in remission as soon as the diagnosis was known, as this had not been previously described.

Illness trajectory related events were chosen as the marker events for this study because it was believed that new meanings associated with these events might be related to process changes within the family. Therefore, change would be more readily detected at these times.

For the first two data collection points individual interviews were conducted with each family member age 5 years and up so that different perceptions of the family experience could be compared, thus providing confirmation of the experience of the family, as well as providing contrasts to individuals' perceptions based on roles within the family (Quint, 1969). Although individual interviews introduce sources of bias in the interviewer's and the family member's perception of the family, the analysis of multiple viewpoints yields an accurate representation of the family unit on the transactional level (Fisher, 1982; Gillis, 1983). Many family researchers have acknowledged the difficulty and expense of observing family transactions (process) as they occur (Fisher, 1982; Gillis, 1983).

At the third interview the entire family was interviewed together. The family interview was the last interview, so that dominant family members' influence on comments made during the individual interviews would be minimized. However, it was believed that a family interview was important in order to observe the family process in action. Family researchers write that family interviews are the most valid way of measuring family process, despite the inherent difficulties of this method (Fisher, 1982).

#### Procedure

Informants were referred to the study by physicians within one week of arriving at a definitive diagnosis. Physician referral was helpful in corroboration of the classification of the child's illness as "good prognosis" and for gaining entrée into the family.



After referral, the investigator approached families in the hospital or outpatient clinic to explain the study and solicit participation. At this time the aims of the study, the procedure and the interview schedules (Appendix A) were discussed. The families were not informed that they were selected to participate because their child had cancer with a “favorable” prognosis, but rather that the study was to determine the experience of the family whose child had been diagnosed with cancer. A time and place for the first interview were also arranged at this meeting. The researcher accommodated separate times and places for individual family members, when necessary.

The interviews were conducted and tape-recorded at places and times convenient to the individual family members, usually in the family home in the evening or on the weekend. On four occasions interviews were conducted with some or all of the family members when they were at the university for a clinic visit. In addition, for one interview, two of the teenage sons were interviewed and recorded over the phone. However, all interviews were conducted in a private place, so that content of the interviews would remain confidential. At the time of the first interview a demographic form (Appendix B) was filled out by one or both parents.

### Validity

Messick (1980) states the case that validity of a study is never established but that the investigator must present evidence supporting the validity of the study. In grounded theory method, validity comes from sampling concepts until the concepts are saturated. Lack of validity comes from premature closure of

concepts. Through analysis and continually sampling and resampling until all concepts are clear and interrelated, the researcher achieves validity. Points that do not fit or are not explained by the theory make the theory invalid.

Presentation of the categories and interrelationships to the body of informants also adds validity to the research findings.

It is important to consider how the investigator's preconceptions and interactions affect reliability and validity. A detailed specification of previous literature, conceptual framework and assumptions allows the reader of the research to make judgments about the validity of the data, the discussion, and conclusions.

### Reliability

Diachronic reliability, the stability of data across time for a single subject, would not be expected in a process phenomenon such as a transition that is characterized by change (Kirk & Miller, 1986). Hence no attempt was made to establish that diachronic stability does exist. Rather evidence of differences in informants' descriptions of their lives at different points in time was emphasized. Evidence of stability of all possible variables over time in this study would raise the validity issues of interpreting the phenomena as something other than a transition or whether the right questions were asked to arrive at the phenomena in question.

Synchronic reliability is a more salient issue for the qualitative researcher. Here the concern is whether observations are consistent with respect to the particular features of interest to the observer. Failure to meet synchronic

reliability criteria forces the researcher to reformulate emerging theory by imagining how multiple, different observations might be simultaneously true (Kirk & Miller, 1986).

Reliability is considered to be adequate when new informants continue to provide redundant information, and when no new categories and no new properties of existing categories are generated by the interview process. To reach this point, usually the researcher will interview informants from divergent groups until they cease to give new information. The present study was limited to a small, circumscribed pool of informants, as the number of children diagnosed with cancer with a favorable prognosis is quite small. The numbers of divergent groups represented in the informant pool may be limited, so that the categories may not have been saturated in the usual sense. However, the categories were saturated with respect to the experience of favorable prognosis childhood cancer. A further study of children with other types of cancer may be needed to flesh out the categories of the transition process following diagnosis of childhood cancer, but that was beyond the scope of the present study.

#### Ethical Issues

The study was reviewed and approved by the institutional review board in order to protect the rights of the participants. Consent forms (Appendix C) were given to the families to review at the time the family was first contacted. Each family had an opportunity to read the consent and consider it during the interval between the initial contact and the first interview. The forms were signed at the first interview. Parents signed consents for all of their children to participate. In

addition, children age 7 and older signed their own consent forms. Children under age 7 gave verbal assent.

Participants in this study did not benefit directly in a measurable way. Informants in similar studies have commented on the helpfulness of having an empathic listener during a stressful time. In addition, others have commented that they like to feel that they have contributed to science or that they may have helped someone in a similar situation. Potential costs to participants were loss of time, intrusion of a stranger into their lives, and contemplation of distressing and emotionally draining material during the course of the interview. Participants were told that the care of their child and other family members would not be affected by their participation or non-participation or by the content divulged during interviews.

Access to tape recordings and transcripts of interviews was available only to the investigator, the transcriber, experts utilized for inter-rater reliability of coding, and dissertation committee members. Names were not associated with quotes in any publications, and identifying information was disguised sufficiently to prevent recognition of individuals as they appeared in reports of the study. Tapes were erased as soon as the interviews were transcribed. The transcripts will be kept by the investigator in a secure place for 5 years after conclusion of the study and then destroyed. Identifying information and interview data will be kept in separate places.

## Analysis

All audio-taped interviews were transcribed. The constant comparative analysis technique was used to form categories of the family experience. This is a process in which the investigator simultaneously compares data from each respondent about a particular topic, going back and forth from transcript to transcript. Grounded theory method specifies that those categories are derived from the data given by informants and not specified a priori (Glaser, 1978). However it was expected that the families would describe changes in family process. Kirk & Miller (1986) describe validity as the issue of whether the investigator really sees what she/he thinks she/he sees. Of particular concern is whether the phenomena are properly labelled. By using labels generated by informants for first level abstractions of categories and by presenting interpretations back to the informants additional evidence for validity can be gathered. Both of these strategies were used in this study.

The constant comparative analysis method produced beginning categories and interpretations by the time follow-up visits were made to families. Therefore, it was possible to validate findings from previous interviews, as well as findings from interviews with others in the study.

The analysis was modified with an analytic strategy borrowed from Heideggerian phenomenology, that is thematic analysis (Benner, 1985; Benner & Wrubel, 1989), in which themes from each family interview were derived. These themes were then compared to arrive at common meanings. Appendix D shows a sample worksheet devised for deriving themes and comparing mean-

ings. Once each family interview had themes derived, the family interviews were cross checked to make the coding and identification of themes consistent and to clarify fuzzy boundaries between themes.

Subsequently, themes were analyzed across interviews and a composite description for each interview time was developed (See Appendix E). At this point it became evident that several themes were appearing in all interviews. Other themes only appeared in one or two of the interviews. The relationships between these themes and the variation within themes were explored and expanded to develop a description of the family transition to living with childhood cancer.

Pertinent variables considered in the analysis included type of cancer, age of ill child, and number and ages of siblings. Variables such as income, educational level (Murstein, 1960), occupation of parents, social support (Morrow, Carpenter, & Hoagland, 1984) and religious affiliation were also considered to be important to note, as the possible variations might have contributed to the experience of the family.

Analysis was carried out primarily through reflective thinking and careful documentation by the researcher. This was done in multiple ways, including beginning to code data and extract themes and categories with the first interview. These interpretations were then introduced to informants in subsequent interviews, giving informants the opportunity to validate the information and interpretations. Analytic discussions with other qualitative

nurse researchers were utilized to stimulate development of coding schemes, categories and theoretical relationships.

The constant comparative analytic method started with an initial reading of the interview transcripts. Preliminary codes were marked on the transcript (Corbin, 1986b) and a list of categories was kept in a separate notebook, with tentative definitions of those categories. The categories were then used to generate probes and questions for the next interview (Corbin, 1986b) and were used also in coding the transcript from the second interview. New categories were added to the list as they emerged from subsequent interviews. Periodically previous interviews were recoded using revised category lists so that new and old data were constantly being compared (Glaser & Strauss, 1967).

Relationships between categories were hypothesized and recorded in "memos" (Corbin, 1986a, 1986b; Fagerhaugh, 1986). There was considerable mental manipulation of these relationships during this phase, as the researcher moved between levels of abstraction, and questioned and tested the relationships between categories. The hypothesized relationships were presented to informants in interviews for validation and subsequent memos documented the revision and reformulation of these relationships. The theory was then refined by diagramming relationships and collapsing lower level categories into higher level categories, to clarify relationships between categories. These statements of relationships between the concepts evolved into the grounded theory that is the end product of this research.

The end product of the research was then presented to selected families, to validate that the experience they had was in accordance with the generated theory. At this time the family members were encouraged to expand on, and reflect on their initial experience with childhood cancer and to make comments on the model. This visit occurred 9–18 months after the diagnosis, in addition to the 3 interviews at set times. In one family the child had been finished with his prescribed chemotherapy for 11 months. For the other two families, the child was still in the maintenance stage of chemotherapy.

#### Limitations

This study was limited in that it did not sample all of the many possible illness trajectories for childhood cancer. Therefore, the theory generated from this study applies only to those trajectories sampled, and other illness trajectories will need to be addressed in further studies. It was further limited by the brief duration of the 3 month data gathering period. There is evidence that the transition lasts longer than the time frame of the study. It was anticipated that other family transitions which might take place in response to critical events in the illness trajectory would not be captured by this study. Rather this study focused on the initial transition at diagnosis of the illness.

Another limitation of this study was the effect of the observer on the phenomena. In this case it was anticipated that the presence of the interviewer might affect the informants in at least two ways. Since an interested listener often enhances coping strategies (Levinson, et al., 1978), the presence of the observer might in some way alter the pattern of adaptation of some of the



individuals in this study. Also, the observer might have introduced topics that might not have otherwise been considered by the informant. This in turn might have affected the course of adjustment and adaptation of individuals and families as they moved through the transition process.

The interviewer may have actually influenced the results by the process of interviewing the participants. This interaction between method and results occurs, according to the assumptions of Symbolic Interactionism, because the meanings and the process of the family are shaped by the interactions that individual members engage in. The interaction occurred in two ways. First, the meanings for individual family members may have been altered by the individuals' interactions with the researcher. Second, the researcher, in encouraging dialogue between the family members in the last interviews, may have influenced the communication process between the family members themselves.

A final limitation in the design was the decision to sample according to trajectory related events such as diagnosis and remission. Because for some families the diagnosis and remission came at the same time, and they did not have the interview at approximately 4 weeks post diagnosis, it was difficult to determine if some of the variation in response was related to differences intrajourney, or if time since diagnosis was also a factor in the response.

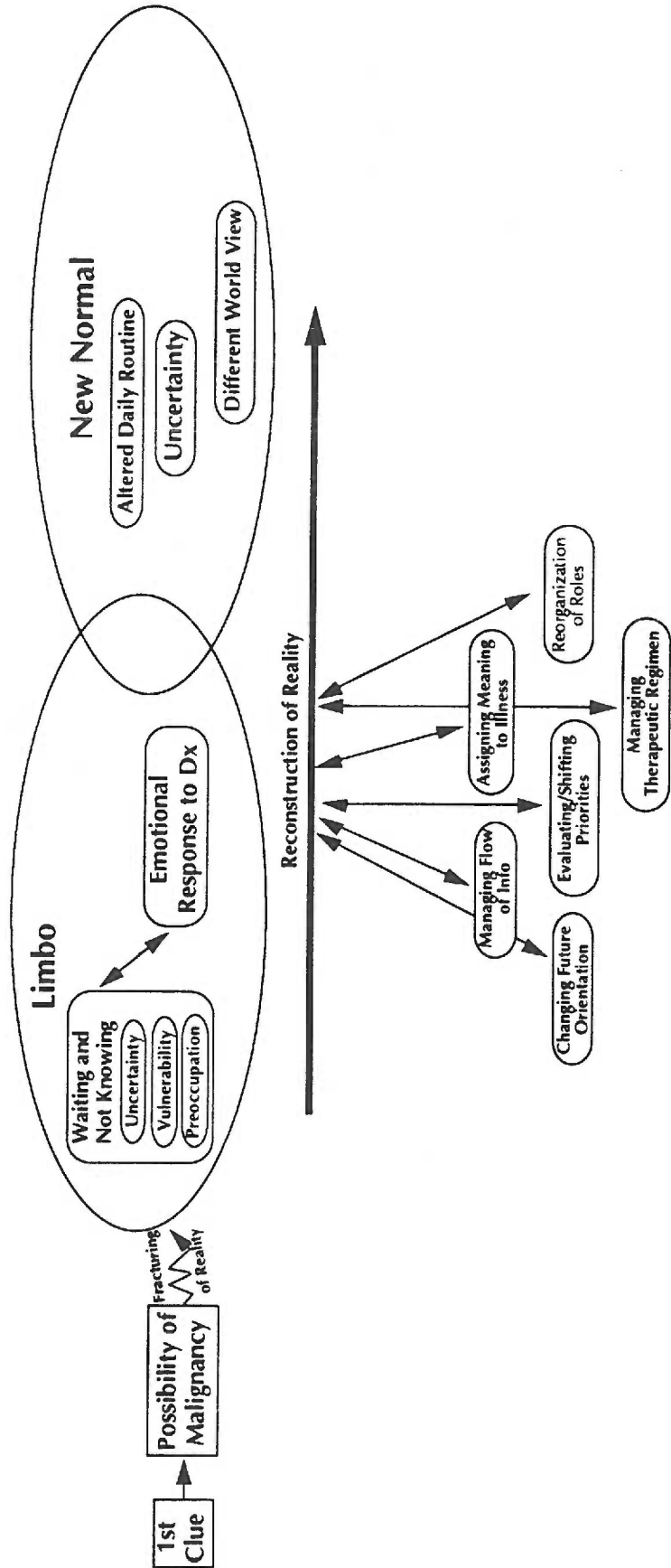
## ANALYSIS: FAMILY TRANSITION TO LIVING WITH CHILDHOOD CANCER

Families described poignantly the transition to living with childhood cancer. Although the process of transition evolved over time, the progression was not necessarily linear, and did not necessarily reflect the phases of the illness trajectory marked by professionals. A graphic representation of the transition is depicted in Figure 1.

The family's transition to living with childhood cancer began when a previously healthy child presented to the parents with a few non-specific symptoms. These symptoms were apparent to the parents and possibly to medical professionals. The transition process accelerated when one or more family members realized that the illness might be either life-threatening or malignant. Once that possibility was recognized, reality had been fractured, life was changed dramatically, and the family was thrown into a state of limbo. Gradually, in the disruption that is the state of limbo, the family members began to engage in strategies to reconstruct their reality, creating a new normal.

It is important to realize that although the model is drawn in a linear representation, the process did not necessarily occur in a directly linear fashion. Although families moved toward the new normal, they did have periods when they reverted to more disorganized ways of coping with the illness for short time spans. In addition, boundaries between the phases of the transition were not clear cut. It is almost impossible to determine the exact point at which a family left the limbo phase and had reconstructed the new normal, and the new normal itself may have been a midway point between limbo and the point at

**Figure 1.**  
**Family Transition to Living with Childhood Cancer**



Prediagnosis

Diagnosis

Remission

which the family reached a stable pattern of dealing with living with childhood cancer.

### First Clue

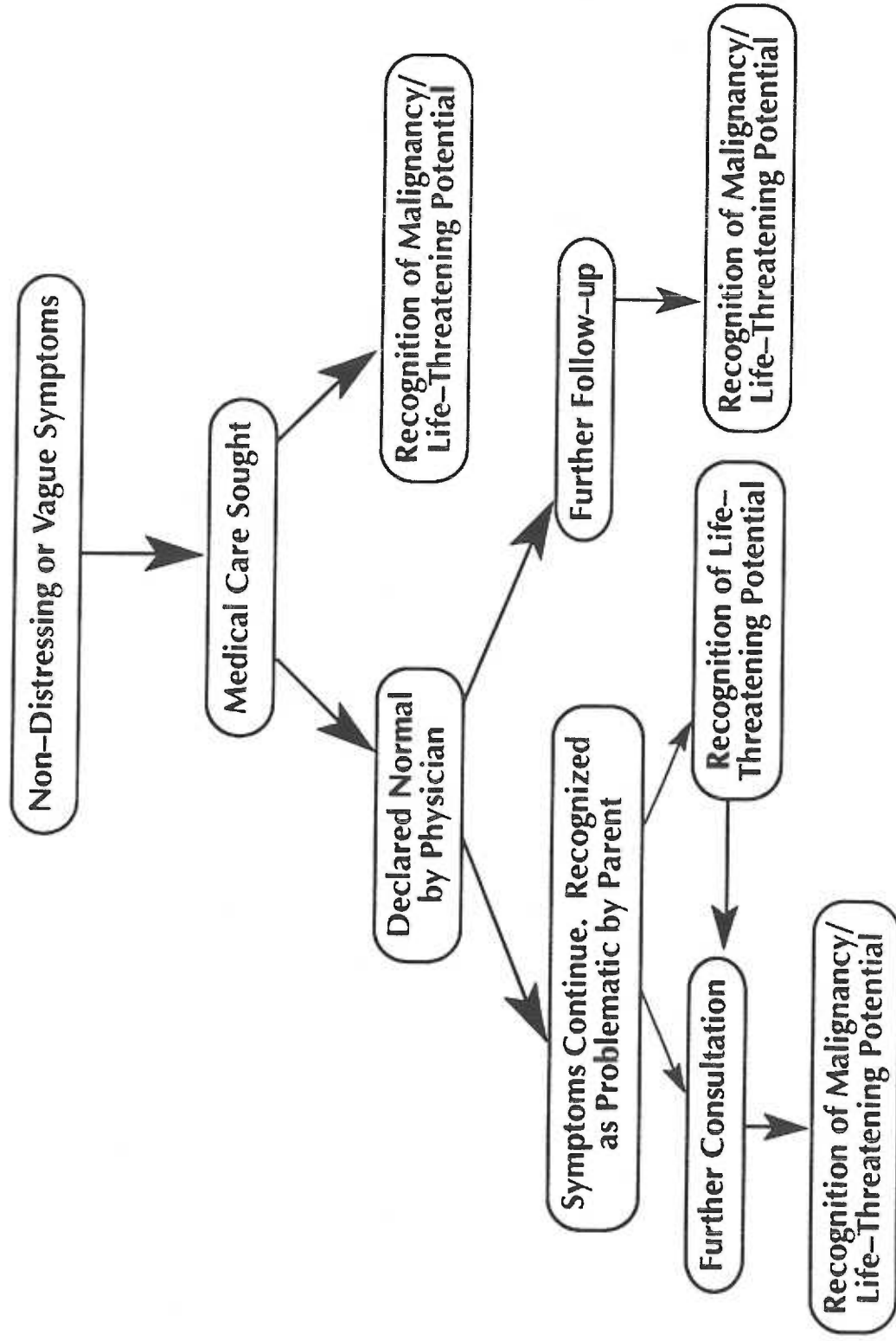
The specific first clue that the illness was serious and potentially life threatening was different for each family. A graphic depiction of the route to recognition of the malignant and/or potentially fatal nature of the illness is shown in figure 2. For some there had been a history of a symptom which had been lingering, one which had been evaluated by medical professionals as nothing other than the usual childhood illness. This was finally recognized by the parents as something more serious, and they subsequently sought or demanded more extensive evaluation. For example,

When she first got sick she was tired a lot and she had a fever for seven days and I took her to the ER because it wouldn't go away and two weeks prior to that, she started coughing really bad and I took her to the doctor for that and he just gave her some cough syrup and then after that, she still didn't feel good so I took her to a different doctor and he said that she had an ear infection and that was five days before I took her to the ER. I guess that they probably could have found out the first time if they would have looked a little closer at what was going on.

In other cases it was the medical professional who suggested further testing, leading to the discovery of the malignancy. In the case where the child appeared healthy except for the one symptom, this caused surprise for the family,

Well, he got a lump and it showed up when we were on vacation. So we

**Figure 2.**  
**First Clue (Initiation of Transition)**



got back from vacation and the doctor said it was inflammation and that the gland would probably go down and later we had him checked again, and our family doctor looked at him and thought the same thing and he checked him for skin tests and...leukemia...and that didn't say anything... So we took him to a surgeon and he said it was a mass and we need to [have it removed] but he...tried to assure us he didn't think it was anything...after they had that growth and that tumor removed, they told me that he had cancer which was a real shock to me. So there wasn't really any warning as far as illness; just had a supposedly harmless growth removed and they found out it was cancer.

In another instance, the parents recognized the life-threatening nature of the continuing symptoms before the medical community did, precipitating a middle of the night trip to the emergency room. The mother described the urgency of the situation,

We rushed him to the doctor at the emergency room because he couldn't breathe at 1:30 in the night. And he did a bronchial inhaler and he felt better after that. It didn't look like there was anything pathological when they looked at the x-ray. So we took him [home]. And we did go back for a second opinion to my original pediatrician, whom I always deal with. And he was wheezing. His color was a little different at that point and when I saw him take his shirt off I noticed his strained blood vessels.

At this point the pediatrician suspected the diagnosis, and an emergency transport was arranged, however, the mother had suspected that the nature was grave and even life-threatening before the doctor announced it. For the father

in this family, the realization was a little later, after the child arrived at the University Hospital:

I felt better knowing at least then that he was [at the University Hospital] and yet I still did not know the urgency of the situation. And as we proceeded, I realized full well that had it been another day or two, they might not have been able to save him.

In the final situation, a lump was discovered in an apparently healthy child. Medical care was promptly sought. The lump was rapidly diagnosed as malignant, even though the child had never appeared ill. As the father described it:

My wife lifted her up in bed. She felt a lump under her arm and she had me feel it and we both decided that it was nothing to mess with so she went to the emergency room that night. They decided to have her see the family doctor the next day. We decided to have a specialist take it out and biopsy it and that was three days later, we had her in for day surgery and that day we found out...She had no precipitating symptoms.

For all the families, it was the recognition that their child might have a life-threatening illness or a malignant illness that fractured reality. For some families the recognition came as a nagging feeling that there was just something not right with their child, for others it was the presentation of a frightening symptom such as shortness of breath, and for others it was hearing from a physician that their child might or did have a malignant disease. This recognition of the threatened loss of their child sent the family spinning into the state of limbo.

## Limbo

The state of limbo was characterized by intense emotional experiencing of events, and a period of waiting and not knowing, uncertainty, and vulnerability. The waiting and not knowing was followed by the emotional response to the illness. In the midst of the upheaval, the family began to utilize new coping strategies and gradually implemented a complex set of strategies to begin reconstruction of reality.

### Waiting and Not Knowing

Waiting to hear a diagnosis or the results of a test, the meaning of a diagnosis and possibilities for treatment was significantly distressing for parents of children who had cancer. Although most of the children did not discuss the phenomenon of waiting and not knowing, from a systems framework one can assume that parental distress impacted the rest of the family. Why it was so distressing relates to several factors. There was the uncertainty and the inability to plan or project into the future while the outcome was pending. Parents did not know whether to schedule appointments in the next week, let alone make plans for years in the future. "That was probably the longest period that we went through. The not knowing exactly what it was, what we had to look ahead for and I think that was one of the roughest times we went through." There was a significant amount of worry as parents imagined the worst possible scenarios. This may have been helpful in planning action in the case of the worst scenario, but more commonly it was tiring, nonproductive worry. One parent stated, "It was long and tiring. There's just lots of waiting, waiting for an answer." It became difficult to think about other facets of one's life. Because of



the preoccupation with the anticipated outcome, work tended to go undone, or was done poorly at best. According to one parent, "Waiting to get an answer is more important than about anything you're doing. Waiting is what disrupted us more. Just waiting to get the facts and get on with the process." Another father described his preoccupation, "I was driving down the freeway, and you know how the freeway gets, it's busy. It was like no one else was there. I mean all I could think about was [the ill child] and it's a scary situation."

Professionals and situations perceived as obstructing the final determination were reacted to impatiently. To some parents it seemed as if most of the professionals with whom the family came into contact did not acknowledge the significance of the results for the family, and they did not share the parents' sense of urgency. Rather than wait a week or even a few days, the parents of a child who most likely had cancer wanted to hear the news yesterday if at all possible: "I just wanted to hear something sooner about a diagnosis."

Despite this urgent desire to hear the news, parents also dreaded hearing it. "At that time I didn't know whether he was expected to die in a month or two or what the deal was." Parents wondered if their child's life would be like that of all those people seen in the waiting room.

I didn't know what it [the chemotherapy] did. I saw these patients while we were waiting for the tests, you know, missing limbs and that kind of thing and so I was wondering does the cancer do this or did the chemo do it, and I had no understanding of what it was all about and what it actually did.

Parents wondered how they would cope with the pain and suffering of the worst imagined case. They wondered about having to make alternate work

arrangements and having to cancel social plans for the coming months. They also wondered if something different had been done earlier, perhaps they would not be here now, or perhaps the news would not be so drastic.

A sense of helplessness overcame the parents as they thought about what might be the worst case. Sometimes a parent also tried to think of things to do in that worst case. This was frustrating because those plans need not be activated unless and until that most dreaded possibility occurred. And that time was yet unknown. One father said,

That was some anxious moments. I was kind of anxious. [It] begins to wear on your patience a little bit, wondering and waiting for all the test results, wondering if just one more tumor is going to be revealed or something like that...I think that what probably brings a lot of stress at the beginning is that you don't know exactly what the disease is and you don't understand the disease and ramifications so you just don't have any idea.

That not knowing is probably the hardest thing we [have experienced]. There was also a sense that regardless of what the outcome was, there was no curative action which could be taken until the cause was known. Even if it was something minor, recovery would be delayed by a lack of knowledge, and parents were anxious to get the treatment started.

The parents felt vulnerable and at the mercy of the professionals who would discover the mysteries of their child's condition, tell them about it and recommend treatment. Not only did the professional control the precious information, but parents needed to trust the professional's competence in determining the real problem. One father said, "They're holding back

information, they're waiting, they don't want to let you really know how bad it is." In contrast another father felt confident that he was being told everything: "We appreciated their candor and honesty, and I think it's important that physicians realize that parents need to know." Both fathers were certain that they did need to and wanted to know everything as soon as possible.

Parents were also dependent upon the physician and other health care professionals to communicate the information they needed to plan and carry out their lives for the next several weeks. The way in which the professionals handled this process, from leaking of information to communicating the whole picture at the end, seemed to have an influence on subsequent trust on the part of parent/patient. When families perceived they had been told all of the worst things that could happen or be discovered as well as the best, they then felt that they could trust the physician to tell them everything

In contrast, in one case a family thought from the beginning that they had not been alerted to the possibility that their child might have cancer and they were surprised to hear the pathology report that indicated malignancy. This family believed that the physicians were withholding information. This belief that information was being withheld was intensified as the family waited 5 days for the diagnostic tests to be completed before hearing results from any of them. They were still perceiving that the physicians were withholding information at the third interview, and asked the researcher if the chart held any information about their child that the physicians had not told them.

Until the final pronouncement was made parents could not grasp the reality that they must deal with a dread disease. This information was crucial to the

adaptation to the disease. In one family the comment was, "I think the most difficult thing is waiting for facts because you're wanting to believe this but you're not sure ." In another family, the mother said, "I really believe that the not knowing is the worst. Because you cannot begin to deal with what you don't know yet."

Sometimes the period of not knowing was marked by a small tidbit of information such as the fact that the child has some form of leukemia or cancer, but the subtype, and hence the prognosis and treatment, was not known. At the time of diagnosis, many family members still believed that a diagnosis of leukemia or cancer was uniformly fatal, and this perception did not seem to be dispelled until the official differentiated diagnosis was made and communicated to the family. "For a couple of days we didn't even know if she was going to live or not. So we were all nervous about that and on edge waiting to find out what kind of leukemia it was."

Some of the agony arose from partial knowledge. For example, knowing that the diagnosis was cancer of some kind led parents to believe preconceptions of cancer as a uniformly fatal illness were applicable to their child. In one case the knowledge that the child would undergo chemotherapy and misconceptions about chemotherapy added to the anxiety. Sometimes conflicting information from local doctors and cancer treatment center physicians added to the agony. Above all, the families found the days of waiting until all the test results were in and before having the discussion about the diagnosis, treatment plan and prognosis to be tedious and filled with worry.

### Uncertainty

Most families viewed the time surrounding the diagnosis as being in a time of upheaval. The normality of their lives had been disrupted in a major way, adding a different kind of uncertainty to the uncertainty about the child's diagnosis and prognosis. There was the uncertainty of how family life would be managed in the coming days and weeks. All but one of the children were hospitalized at some point in time during the diagnostic period or immediately afterward. Parents reported taking time off from work, and for many families, they had to arrange alternative child care for siblings. There were some concerns, particularly on the part of mothers, about being able to care for the child as well as carry out their work responsibilities. In those families in which the mother decided not to work for some period of time there was also added financial uncertainty. Families stated that the time before diagnosis was one of preoccupation and worry, so that they were looking forward to being able to relax and get some escape or relief from the emotional distress. With the exception of one family they expressed that they were looking forward to or hoping for the certainty of a return to normality in the near future, once they knew the diagnosis.

### Preoccupation

Preoccupation with the illness and its effect on the lives of family members were discussed by some family members. Two parents talked about how it was so awful to wake up in the morning and realize that the illness was still there. A mother said, "The scary part the whole time of being in the hospital was dozing off and waking up and you are still there." Another father commented, "I had to

come to grips with reality, that when you wake up each morning that you still have to face it—it did not go away during the night.”

In later interviews, family members remained preoccupied with the illness, although some did return to many of their usual tasks and jobs. One mother described it poignantly, “And I’ve found myself just [sitting and thinking about it] and just pondering and crying and crying.” For another father the preoccupation came in the form of making plans to ameliorate the affect of the illness. One sibling also talked about the preoccupation related to the illness of his sister. The researcher commented, “I can just imagine the teacher calling on you and you’re like, ‘What, what?’” The sibling responded,

That’s happening, that happened today because I knew that she wasn’t feeling very good. It’s hard to do things because you worry a lot. I wonder what she is doing and everything. If she is going to fall or twist her ankle or something. I’m afraid she is going to fall and get hurt because she is still not very strong.

### Vulnerability

The diagnosis of childhood cancer meant that the family suddenly realized that they were vulnerable, as they stated that they did not think it could happen to them. One mother said, “I felt that this always happened in *McCall’s Magazine* or someone from North Carolina. Their child got sick, but never mine and now it’s your own child and you think, ‘OOOH’.” Another father put it differently, “It made me extremely aware that I was not exempt and that those vulnerable things can happen without any advance warning.”

### Emotional Response

The prediagnosis period was followed in all cases by the pronouncement of the diagnosis in a family meeting with physicians. During this meeting the diagnosis was given with a percentage figure for long term survival. Initial treatment plans were discussed at this time. All of the families said that hearing information about the diagnosis of cancer was a shock, although for some families the fact that the child had cancer did not first become known at this meeting. Some families who already knew that the child had cancer felt that the meeting with physicians was also shocking and traumatic. This is in part due to the finality of the conference and having to let go of the possibility that there was some mistake and that the tests would not show cancer. One parent gave as a reason for not wanting to know, "I did not want him to tell us because it was official." Not knowing was horrible, but knowing removed the uncertainty that allowed the hope that it was nothing serious and brought the horrifying necessity of confronting the disease.

The families met the challenge of confronting the disease with denial at some level. No family went so far to deny the existence of the disease, but denial took the form of refusing to acknowledge the significance of the disease or events related to the disease, choosing not to think about the future, and statements about hoping that they would wake up and discover that the illness was all gone, or a mistake. One mother said,

There are even some days now that it doesn't seem real. Even though there are times when it seems very real but other times it is 'This isn't

happening. I am going to wake up. It's all going to have been a bad dream. It hasn't happened, to him or to us.'

Additionally many family members were angry that disease had happened to one of their own. One father actively defied the disease, saying, "There's no way she can have cancer. I was defying what he was telling me." Shock was also universally reported among parents and children. Not all people showed all of these reactions. Many families also expressed relief that they knew what it was, that it had a good prognosis, and that they could begin to fight it. As one parent stated, "That knot went away because we knew what it was and they had given us a lot of hope and then we could deal with it. You cannot begin to deal with what you don't know yet."

#### Strategies Used to Reconstruct Reality

Gradually the family begins to use strategies to reorganize their lives and they construct a new normal. New normal for these families was a new routine marked by efforts to manage the medical regimen, efforts to maintain normative growth and development of family members, and an altered world view. Strategies used to reorganize their lives include reorganizing roles within the family, evaluating and shifting of priorities, managing the flow of information, assigning meaning to the illness experience, and managing the therapeutic regimen.

Some families described systematic efforts to reconstruct their reality whereas others had a confusing array of strategies that they used somewhat inconsistently. One family systematically dealt with all the unexpected setbacks their son experienced by just taking one day at time, and not borrowing trouble



by worrying about what might happen in the future. When confronted, this family also dealt with crisis by denying the magnitude or significance of the problem. When all else failed they would “just deal with it” and endure. In this way they never had more than they could manage at one time. For another family the coping was through intellectual mastery of the illness. This family sought opinions from experts, read about medical and psychological treatments, and tried to establish a “healthy” atmosphere in their home in which the ill child was happy and experienced a minimum of stress. For yet another family, the coping efforts were focused on setting up a system of care for the youngest of 5 children in a home where both parents were working. The three oldest children had a system to remember each medicine and administration times, as well as a system to record the taking of the medication so there were no duplications. They took turns doing the personal care. The sister bathed the ill child while a brother shampooed her hair because the sister was afraid of the hair loss. The children knew how to and did call health care providers when questions arose. The mother was confident in the quality of care her children gave. She had even arranged for one of the older children to give medication during class at school.

#### Reorganization of Roles

Families began redefining roles with the initial hints of serious illness. For some families these role definitions were subtle, often redistributing time in different percentages among work and child care roles. In other families, the role redefinitions were blatant. For example, one father gave his job a second priority and assumed most of the care of the ill child. This meant that he gave

up a lot of community service activities and assumed a greater role in emotional maintenance of the family than previously.

The worker role was one which often needed to be redefined. Parents perceived that work settings were tolerant of absences for this diagnostic phase of the illness. Some even indicated that the work settings would be tolerant of continued absences, whereas others did not feel that extended or frequent absences would be tolerated. For two families, although absences would be tolerated by the work setting, the loss of pay would or could not be tolerated by the family. Mothers seemed to do the majority of role redefinition. Three mothers felt that they would have to give up their work obligations to care for the ill child. One returned to her occupation in between the second and third interview and another found some work that could be done in the home. A third mother, after some soul searching, decided to continue with previous plans to start working after more than 17 years of raising her children. This was possible only because (as mentioned above) the father redefined his roles within the family and at work to allow for more time at home and assumption of care duties for the ill child.

Although none of the other fathers had such extensive changes in their roles, many took on additional child care responsibilities after the illness. One father took turns with his wife taking time away from work to go to clinic and hospital treatments.

All families described efforts to normalize discipline and routine as a means of helping the ill child cope with the illness and of increasing family stability. Most parents felt that the child's psychological state would affect the physical

response to treatment. There was concern about balancing the need for usual limits and punishment and the need to alter those due to the illness. One father describes the dilemma,

“As for disciplining or telling her this or that, we try and keep it the same but you can’t the way her emotions are running right now. We give her a lot more leeway. Some things that she does if it was any other kid not sick, you’d have to jump on and straighten them out but we let a lot of things ride with her. We have to give her a lot more patience and give her a little more slack because the medicine does do terrible things to her and [it’s hard] to know when it’s medicine and when she starts play it for a few things. There’s a fine line there that you ask yourself, ‘Should I control [her behavior] right here or maybe it is the medicine and maybe [I] should just let it go by. That is a real tough one to figure out.’”

One father thought that making his son’s environment as non-stressful and pleasant as possible would help his son both psychologically and physically.

Families had to decide how much responsibility individual family members would have for managing the therapeutic regimen. In some families this fell primarily on the mother. In others, both parents shared almost equally, and in others some of the siblings assumed a large share of that responsibility. However, ill children usually played some part in this management. For example one 2 year old had the following change in her assumption of responsibility, “At first it was so hard giving it to her because she just fought and fought and fought to take it; now she reminds me.” Another family gave the 5 year old son responsibility for taking his medications, and worked to instill in

him an attitude of fighting the illness. The father said, Like I told him, well if you want to get sick and die and don't take these, don't take them. I can't force you to take these pills, if you want to do that, that's fine. And after about two times of talking like that, you know, he's had no problems taking pills.

#### Evaluating and Shifting Priorities

Family members found that the diagnosis provided a stimulus to think about the priorities in their lives and many either planned to make changes in their daily lives to reflect more clearly the values they held dear or changed their priorities as well as their life plans. Most commonly this reordering of priorities and activities related to bringing the family closer together, valuing time spent together, and appreciating the small things in life. In addition families found a need to reorder their time perspective. The need to "Take one day at a time" was expressed by many families. In addition, many family members were hesitant to consider what the future might hold.

During later interviews, family members (primarily parents, although a few of the older children also) continued to talk about evaluating their priorities and making changes in their lives as a result. Most families had taken steps to put into action their changed priorities.

The guys wanted me to go [elk hunting] this year and I told them I really can't. I didn't want to go, I really don't. I don't have any interest in anything of a nature that would take away from the time I would have with [my son] and my family. I get so much vacation time and I am pretty

much going to use most of it for the trips back to [the University] and stuff. And I am real comfortable with that. It's something I want to do.

For some families, the priorities had not changed in the same way for all members, which caused some strain and conflict. "Well, I'm not thinking long range. Before this happened I'd say, well we'll save and when we get enough money, we'll go to Disneyland. And now I'm saying, well, let's plan to go to Disney World Spring Break. And [my wife] will say, well, we don't have enough money, and I'll say, then we'll borrow it." The father is wanting to seize every opportunity for his son because of the uncertainty of the future. The mother, on the other hand, has the hope that there is a need to save for the future, that her son will survive and live in the future. In addition, since he will be living in the future, he needs to have as normal a life as possible, and not be spoiled.

The most common priorities which changed were related to the value of family closeness, time with family members, and enjoying the small victories and pleasures of life. According to one father, "We have looked at our lifestyle. And basically at the part where they say they ain't feeling good or something like that and being home with them more often. Being right solid." His wife added, "It makes you appreciate [the children] more and you know, set back and realize how short life really is."

By interview 3 some families were saying that their basic values weren't really changed, but they had started looking at many of the day-to-day rituals and activities, evaluating them for how they contributed to the family's core values, and making changes based upon that evaluation. One father said,

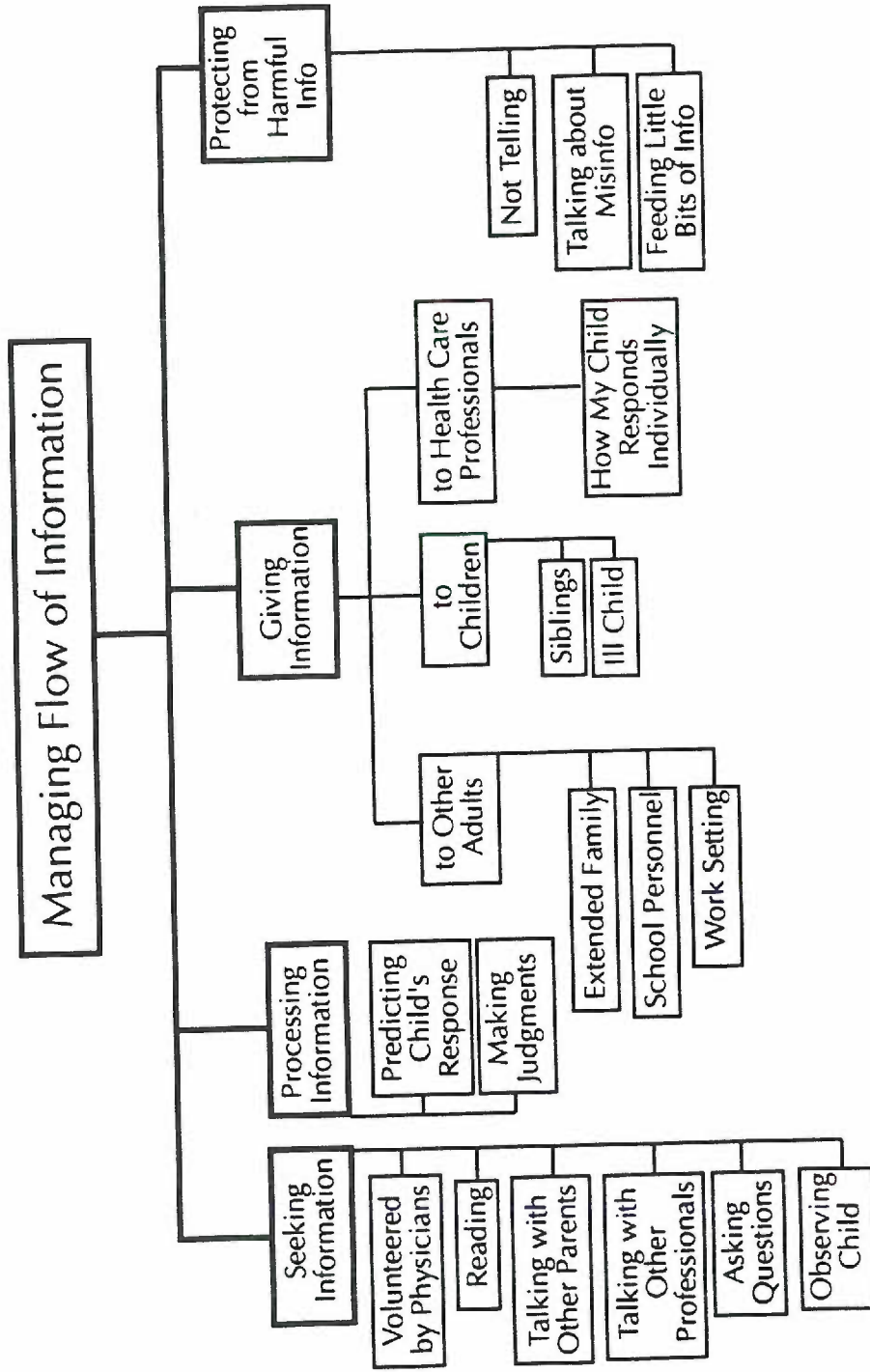
I haven't changed my value system, what I feel is important or things that we believe hasn't changed at all. In fact, I just believe them more. But we find that what's really important [is to] to live one day at a time, taking what you have. You can't really always guarantee the future.

His wife added, "On the one hand, it seems like things aren't a big issue, but then on the other hand, some other things are that you know wouldn't be otherwise." Another father comments in the same line, "Everything's pretty much unknown anymore. Before it used to be kinda complacent like we take everything for granted and things just are different. It was probably there before but wasn't really focused on, really wasn't thought out."

#### Managing Flow of Information

Managing the flow of information related to the illness was a major task of the transition, and involved many tasks including but not limited to: seeking information about the illness, treatment, etc.; processing information about illness and treatment; giving information and explanations to other adults—family, friends, school officials; giving information to children, both ill and well; protecting children (and others) from harmful or dangerous or frightening information; adding to one's personal body of information by observing the child and his reaction to treatment; making judgments about the child's reaction to treatment and predicting future reactions; and communicating information about the child's personal reaction to health care professionals (see figure 3). Some families used the information management mode as a means of coping with and mastering the illness, for others managing the flow of information was one more task to be coped with. For example, one mother described telling

**Figure 3.**  
**Managing the Flow of Information**



others of her child's illness as "helpful" whereas another mother tried to avoid encounters in which she would have to explain the illness.

A prominent task before and immediately after diagnosis was seeking information about the illness and processing it. Most families relied upon the discussions with physicians and nurses as their principal sources of information. One father talked about seeking information from other physicians as a source of additional information. This effort continued at the second interview for this father. As he put it, he had to do it for himself, to know that his son was on the best possible protocol for his particular type of lymphoma in his particular site. This father was more confident in his son's physician than many of the parents, so it seemed that the quest for information was not due to dissatisfaction with the care received. After gathering all the information, this family decided to continue with the original oncologist and treatment plan.

Communicating information about the illness and treatment related events to children was clearly an important task described at the first interview. The physicians encouraged parents to share truthful information about the illness with ill children and siblings at a level that they could understand. Telling the children was difficult for some of the parents. One mother says,

I was just real hesitant to tell [my son] or to [tell] the kids. I just thought why do they need to know this...until or if the time comes. [But] the doctor said, 'No you need to be straight forward with all of them. Otherwise if something happens later down the road, they won't trust you.' So we sat down and we just told them exactly what we knew."



The issue of whether to tell the children, and what to tell them arose in about half the families. Two of the families believed that the children (ages ranging from 0–9) could not understand and should not be burdened with the knowledge. In response to the question of whether the children asked questions about the illness, one mother said, “Thank God, no!” Others thought that the children had limited capacity to understand, but tried to communicate some level of understanding to the children and believed that it was important that these efforts be made.

Some of the families were already expressing concern for how their children, both ill and healthy, would respond to the illness and the subsequent changes in the family. One mother said,

The [children’s] response puzzled me quite a bit. My older one cried, which is what I expected. My younger one, both my younger and [my son] says, ‘Well, can we go to Silver Falls now?’ This conversation we’ve had enough of. [The middle daughter] never really has. She’ll just kinda wonder about things. She will ask him about what did the doctor do to you. She’s real curious about what happens up [at the clinic]...and what kind of toy he got. She hasn’t really seemed real broke up about it.

Families talked about having to tell friends, extended family and the work setting about the illness. Some found this to be a difficult task, and others found the process of telling others was helpful. This difference seemed to be more related to individual preference and coping style rather than timing, who was told, or the response which was received. One mother said,

I at the time didn't think we should tell anybody until they completed the testing. I don't know, I just kept thinking that they might find that everything's OK and I just didn't want to tell anybody, but the doctor convinced my husband that you need to tell people, and I didn't know why at the time, but now I do. That week of waiting was just hell. And we needed those people.

Certainly intervention by the physician in encouraging this family to utilize their available social support was helpful for this family during a very difficult time. Later this mother talked about taking one of the siblings to a carnival just after the diagnosis, "I didn't want to go for one thing cause I didn't want to see anybody and I didn't want to talk and you know, I didn't want to answer questions or anything like that." In contrast another mother said,

I've found that it helps because while talking to them I am sort of studying the stuff that I know. It is kind of like a crash course or I am cramming for this test or something. I feel, I would rather that other people come to me or [my husband] and ask, 'How are things', 'What's going on?' 'What do you have to do?' rather than getting the story someplace else or getting it all mixed up and having them think something really terrible...And it helps me to talk about it.

In two families, one parent had to inform the the other of the diagnosis of malignancy. For one father,

And two days after they had that growth and his tumor removed, they told me that he had cancer which was a real shock to me. So there wasn't really any warning as far as illness; just had a supposedly harmless growth

removed and they found out it was cancer...and I found it very difficult to tell [my wife].

A mother who took her child to the doctor's office describes the scene,

So while the doctor made the arrangements, I said, 'Can I have a phone, I am going to have to call [my husband] right now.' So I called him on the phone and I just started crying. I just said, 'He's very sick,' and he said, 'Why what's wrong?' And I said, 'They think he has leukemia.' And he just went, 'No, No.' And I told him what we needed to do and he said he would make some calls.

Parents also needed to communicate facts of the illness to persons in their work settings so that they could take time off for the child's testing which very often took place at a facility distant from their home. In five of the families, the child was also hospitalized at this time.

Several parents mentioned how helpful it was to talk with other parents of children with cancer and even the children themselves. One parent said of her contact with another mother,

We'd been down to where they get the bone scans and seen some horrors. And I came back upstairs, and there was a little gal that had chemotherapy, and you know of course she didn't have her hair, but, we were in the room watching the movie with her and her mother. She was real bouncy, and bubbly. She'd been on it since July and that helped a lot, just seeing someone that had their spirits together.

By the time of the second interview, in the remission phase, parents wanted to ask lots of questions about their child's illness and treatment and the

expected reactions to treatment. For one family, the father's repeated questions to the physician were referred to by the rest of the family members as "bugging the doctor". One mother described poignantly how she felt asking the questions,

I feel stupid. You don't want to be made to feel stupid when you ask questions...How do you expect me to remember? I don't know what the heck I'm doing. I've never done this before and so I think that's real important. And to let you know, this is normal, this isn't normal, you are doing everything that you should be doing, this is good, this isn't so good, but not to just let you kind of hang there. To understand that if we ask stupid questions it's because we don't know. You may have seen two hundred, two thousand patients. This is so routine they can do it blindfolded, it's no big deal. But treat this person like the traumatic experience it is. We just ask stupid questions so we in our simple way make sure we understand it. And that's why I always ask questions and repeat things and because I want to understand it. I want to know and understand everything that's happening to him and what to expect and what's bad and what's not bad.

Another angle to seeking information from physicians was making sure that the parents were getting the whole story. One family, at the third interview mentioned this concern, "I think it's difficult for families with cancer, they always have to fight the feeling that the doctors are not telling them everything."

Most of the families did not seek second opinions once the pediatric oncologists confirmed the diagnosis. Although family members did not give

reasons for this, financial limitations in several families seem to be obvious factors for not seeking second opinions. Also the fact that many families were referred from outlying communities, seemed to engender an attitude that the University was the authority and where the specialists were. There was not much recognition that anyone else would know any more about or any better how to treat childhood cancer. One family, required by their health insurance carrier to switch oncologists, was greatly relieved to find that the new doctor thought that treatment should be the same and did things the same way as the original oncologist.

As treatment progressed through the months after diagnosis, communicating information to the ill child about ongoing treatments and procedures was an issue for several parents. It was a matter of balancing the need for truth and the need to reduce the child's anxiety. One of the mothers described her concern,

The only thing he wants to know, he keeps saying, 'Am I going to have to have another bone marrow' I keep saying, 'I don't see it on your protocol right now and I'm not sure...' I wouldn't have been lying to him but also it would kind of release his anxiety a little bit. Because I wasn't positive and I told him that I didn't know. And that's probably the way I treat most of it. If I cause him less pain and anxiety I have not lied to him, I've sometimes changed it a little bit if I can by saying, 'It says here you're probably not.'

During the maintenance phase, communicating disease related information to the ill child is not as prominent a task because the treatments had settled into a routine, and there were not as many changes, new situations and

developments. However, some families were still concerned with discussing the illness with the ill child. One father says, "He handles it better if he doesn't talk about it. Sometimes we've made him talk about it. Just he's pretty sensitive and he just wants to do it, get it over with and just go on." For another family talking about the procedures was still important, "I tell her the day before that we're going to go tomorrow. She doesn't like to know." The father described his communication during the procedures, "Talk to her, get her mind off what's going on. You can't really do it very good but get her interested in the bandaid or something."

Some activities to enable flow of information to and from siblings were also engaged in at the time of the third interview. One father described his son seeking information,

Periodically when I come back home, you'll say, 'How's [my brother] doing?' and I'll say, 'Fine,' and you'll say, "Are you sure? Is there anything you're not [telling me]?' Well like last night, last week the doctor called me and it had to do with the typing and I wasn't home and the message was on the machine and [my middle son] is very sensitive to that and he called and said, 'The doctor called and is everything all right?'

Parents also had to coordinate treatments and medical appointments. This sometimes involved reporting counts done at a local clinic to the oncology clinic. One mother described proudly how she could report the different parts of the white count and she even understood what the different cells do and what it meant when the counts had different values.

### Managing the Therapeutic Regimen

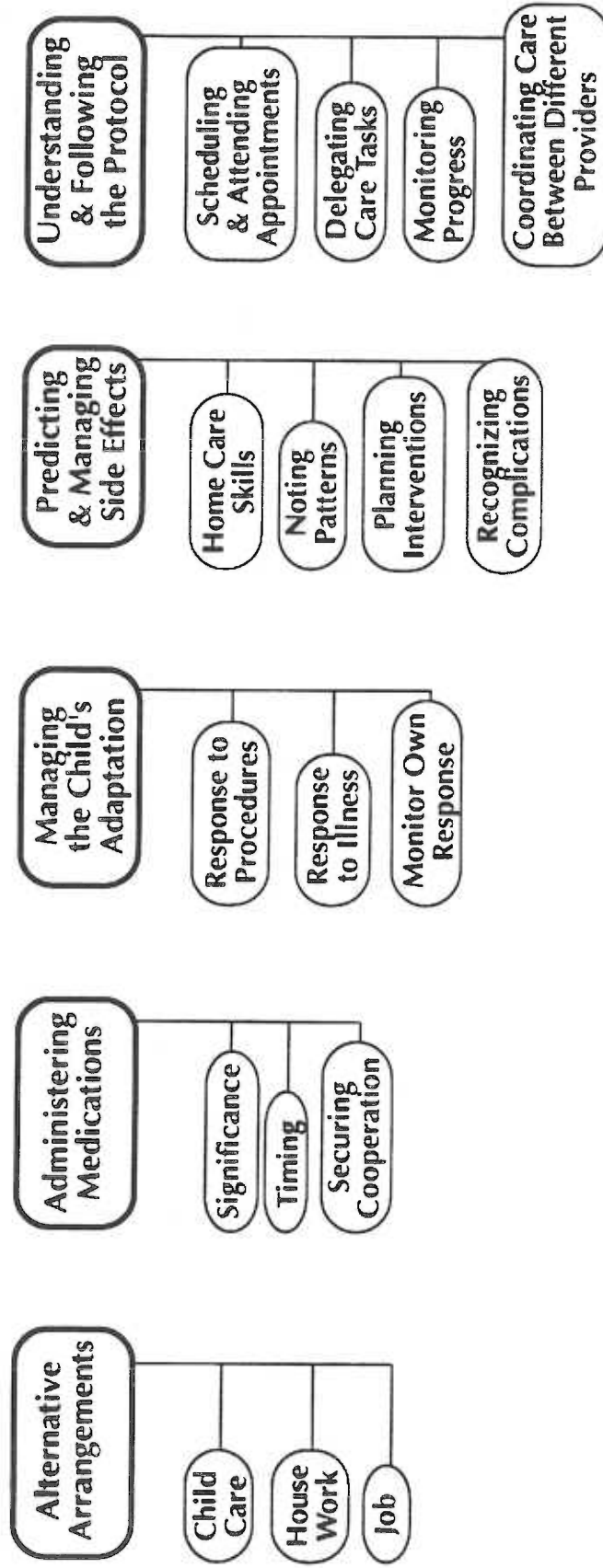
As soon as the diagnosis was definitively made, treatment began. With the possibility of treatment, concerns about the management of the child's medical regimen arose (see figure 4). With the younger children, administering medications was a recurring problem that had to be dealt with several times each day. Parents believed that the medication had life and death significance. Therefore the moments of trying to get the child to take medications without vomiting became tense. Mothers also had questions about whether they should give the medicine again if the child did vomit.

The time required to get the child to appointments which initially were frequent was another concern, especially as all of the families lived 25 or more miles from the University where many of the treatments were done. One mother described spending most of one day taking her child to the doctor for blood tests, getting a urine sample, having an IV injection, and receiving intramuscular l-asparaginase which requires the child to remain in the office for 1/2 hour afterward. She stated,

I was just so thankful that this is all I had to do today. It's all I had to do today was just sit here for four hours in the bathroom at the doctors office trying to go to the bathroom. And that is what has changed really is that you can't put more expectations on anything except whatever you are doing right at the moment.

For some families finding child care for siblings during appointments was also a time consuming activity. The father of four children under age 5 described the task,

**Figure 4.**  
**Managing the Therapeutic Regimen**





Getting babysitters for the next time. [We] hate to wear out our welcome at certain places and try and spread it out so it's no burden to anybody. But it's something that you've got to come up with three times a month and [we] have to sit down and figure out who might be talked into it next time."

After a month to six weeks, the children went into a different phase of their treatment which was less intense than the initial phase. There was still quite a bit of work managing the treatment schedule, with fairly heavy doses of medication for many of the families, although it was not quite as intense as initially. "She doesn't have to have her shots in her leg anymore. She was going four times a week, three times a week; but now she only has to go once but it's further. So it's kind of about even still." Another mother commented, "It's a lot easier now, and there isn't all the massive trips to [the University]. There isn't all the problems from the medications, so now it's gotten real easy now compared to that first month." It was a bit easier, and some of the children began tolerating the treatment better as one of them stated, "Most of the stuff I've been getting doesn't really do anything anymore. Like it doesn't give me stomach aches or anything."

Although some children were tolerating treatment better, not all of the children were. In particular, one of the children was suffering from bacteremia and other complications of treatment at the time of remission. This led to further medical treatments which had to be managed by the family, including a second hospitalization. This same child continued to have difficulty taking oral

medications and required tube feedings through a nasogastric tube, further adding to the burden of managing the medical regimen. The mother described her reaction and the sense of responsibility she felt for her child's well-being,

It was horrible because it was a battle to get him to take those pills and watch him throw up and it was horrifying to see him with this rubber hose sticking out of his nose. It was very difficult. But there is just something in you that starts when they are an infant and you do what you have to do.

In addition to managing the appointments, the parents had to help manage the child's response to the treatment and cope with their own reactions to the painful spinal taps and bone marrows.

Last time she had [a bone marrow], I watched and I about died. It was so hard, I never realized what they did. But she's good. She does really good. I'm really proud of her when she has her treatment. She doesn't really fight, she screams a lot because she doesn't like to be held down but she doesn't fight them or kick or nothing; she's real good. She screams quite a bit but she does real good. She always has to have a bandaid when she's getting her spinal taps and stuff done. She has to hold a bandaid in her hand because that means it's almost over when she has her bandaid. So there's little things that make it easier for her.

In one family the siblings took on much of the care of the ill child because both parents were working. The teenage caretakers talked about both the emotional care and the physical care involved, "you just have to give her a lot of care and a lot of love. And have a lot of understanding and patience." And another brother said, "I've been helping her on and off the bus and stuff.

Giving her medication at school. I go over to her school and give her her medicine and stuff. We take turns.”

At the second interview, some parents began questioning if the treatment was working, especially if the child had not adhered exactly to the protocol. Many of these parents did not seem to realize that the protocols include a reduction or delay of doses if there are complications or too much toxicity from the drugs. “Anyway we were real concerned that through all the infections and they halted chemo for ten days while he was in the hospital. I was real afraid that something happened as far as that.”

One mother talked in detail about trying to find patterns in her son’s reactions and to predict those responses so that she could better manage them. She also described the effect of taking prednisone and how gratifying it was to be able to feed him when he had an appetite on the prednisone as opposed to being a nag when he was not on the prednisone,

It was a joy for me to feed him and feed him and feed him. And now, that took his appetite and that’s scary too because I want to make sure that he is getting the right nutrition. Because now I’m forcing it. Now I’m starting to become a nag, you know, no one wants to be a nag.

This mother also was concerned about screening visitors to the house in order to protect her son from the potential for infection, “That’s my first question, ‘Are you feeling okay? Is anybody in your family sick?’ Then if not, I will let them come over.”

At the third interview, concerns were still expressed about the medical management of the illness. Protocol issues were still prominent, particularly

regarding the child's prognosis if the protocol was not followed to the letter.

One family who experienced randomization to a maintenance arm versus a late intensification arm was relieved at the outcome. It was interesting to note that in the one case, families were worried that the treatment would not be strong enough, and in the other case, the family was relieved the child had been placed on the less intense of the arms. The diversity among these families' interpretations of the protocol related information, served to highlight the significance of personal meaning of events and information. Cognitive understanding was not the sole factor in how the family interpreted the child's prognosis and progress. Their personal interpretations of the illness-related events also shaped their understanding of their child's condition, their responses to the child's condition, and the uncertainty they experienced in relation to the illness.

Most families remarked that the ill child was feeling much better, even when compared to the remission interview. One mother stated, "We never thought it could be this good." All of the children were back in school, missing days only for treatments, and the occasional virus. Because the treatments were less intense and less frequent, managing the regimen was easier. In addition, even the youngest children were taking oral medications without difficulty.

#### Meaning of the Illness Experience

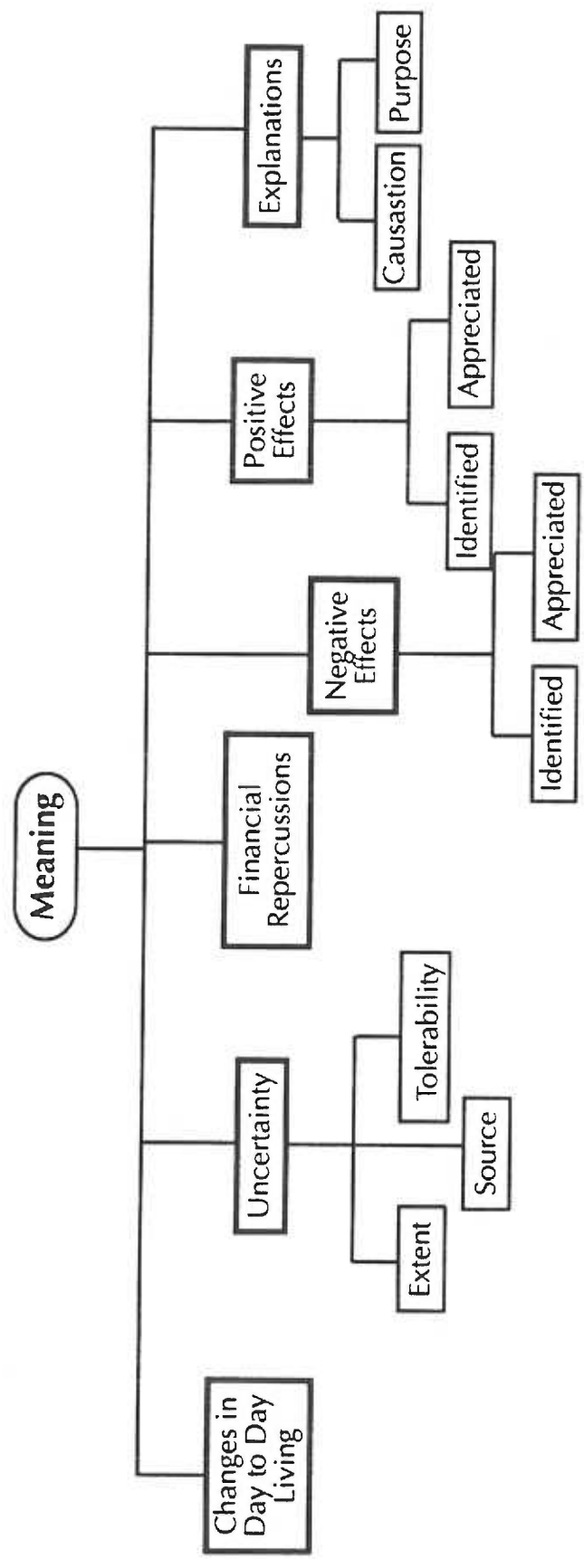
There were several dimensions along which families typically assigned meaning to the illness: 1) day to day changes in living, 2) degree of uncertainty about prognosis and how intolerable that uncertainty is, 3) source of uncertainty, 4) financial repercussions and allocation of resources 5) ability to

see and appreciate positive effects of the illness, such as family closeness and 6) explanations for the illness and why it happened to them, such as religion or fate (See Figure 5). The process of assigning meaning began in the prediagnostic period, continued through the diagnosis and was ongoing as the illness trajectory unfolded with remission, complications and the child's doing well on maintenance.

Meanings for the illness experience began to be developed during the prediagnostic period. For some parents this period involved repeated visits to physicians who reported that there was nothing wrong other than the usual childhood illnesses. This resulted in anger in some parents and/or a lack of trust in those physicians. For one family the repeated physician visits meant guilt that they had not sought a second opinion sooner. The repeated physician visits did not alter the shock of the initial diagnosis or the sense of agony accompanying the testing and workup which immediately preceded diagnosis.

Actually hearing the diagnosis was experienced as shock, although that shock was mingled with relief in some families. During the intensely emotional days which followed, emotional reactions served to carve out many of the lingering meanings for the illness. As during the prediagnostic period, misconceptions about cancer and its treatment lead to the assignment of an immediate threat of death as the meaning of the illness. Because of the nature of the conference when the diagnosis is discussed, these misconceptions were rapidly modified by meanings of hope as survival rates and the effectiveness of current treatments were shared with parents.

Figure 5. Assigning Meaning to the Illness



“Hard” was another meaning assigned to the illness, and related to the emotional difficulty of coping with the illness, the tasks which must be quickly accomplished to initiate treatment, and the physical suffering of the child as treatment was begun. This word was repeated by many family members in most of the families, and with an intensity which belied the simplicity of the phrase, “It’s hard.” Possible deeper meanings of this phrase included the relentless nature of the illness. Perhaps it was a subtle statement that the illness was beyond enduring by oneself. Additionally, as described previously, the diagnosis of childhood cancer also meant that the family suddenly realized that they were vulnerable.

Although the meaning of the diagnosis and the intense emotional reaction to the diagnosis were not prominent features of conversation at the second interview, a few parents still had lingering issues related to the diagnosis. For the father in one family, the anger that his child could have leukemia lingered. In another family, there was still anger, guilt, and blame that the physicians had given it a little more time when the child first had symptoms.

I wish that doctor [wouldn’t have told us to give it more time]. I wish I hadn’t given him time, given it a couple more days [before seeking a second opinion]. Given a couple more days and it wouldn’t have been as serious, life threatening. I’m a little angry about that cause I didn’t want to see him go through all that pain and anguish that could have been helped.

When the medical event of remission occurred, families to varying degrees constructed meaning for that event. The second interview was only done with 4 of the 7 families, as the other 3 children had been in remission at the same

time as the diagnostic surgery. The remaining families had varied understandings of remission. Most of the families (including those families whose child was in remission at diagnosis) could give a brief, scientifically accurate, simplified explanation of remission--the cancer cells are gone but they could come back. The interpretation of the fact that the cancer cells were no longer detectable was perhaps most varied. One family agonized over the fact that the cells might still be there and were concerned that chemotherapy might not be strong enough. The father in this family had a hard time dealing with the uncertainty. Although there was 75% chance for long term survival, all he could think about was the 25% chance of death. In this instance, as in many others, it was the meaning assigned by the individual family members to bits of information which was significant for the family, rather than the actual facts themselves. Other families were more influenced by the child's visible condition as a determinant of the meaning of remission. One mother told me on the phone, "I don't care what they said, she still is not feeling well, she is not in remission." Another family whose child was hospitalized at the time of remission with bacteremia and an ileus were so concerned about that illness episode that the remission went almost unnoticed.

I was more worried about the other part, the staph infection. I guess you're supposed to be real happy and stuff, but he was still real sick. After I think about, it was real great. We got home and it was, 'Yeah, the leukemia is gone, that's great.'

Other families, whose children were visibly improved at remission time,



expressed relief, and a guarded happiness. The happiness was always guarded, however, because one did not know when or if the illness would come back.

At the second interview, family members had been thinking about the illness and assigned meaning to the illness and its occurrence in their family. One family felt that having to deal with the disease was tough, but that there was some reason for it. However, at the point of remission, the meaning of the disease remained hidden from the family members. This family was able to identify several positive outcomes of the illness experience. They also put it into perspective by saying, "It's just a disease."

Two of the fathers at this interview referred to the responsibility they had to support their families. One father believed that it was his responsibility to guide the family emotionally, to get them to pull together and to assist each individual in his/her coping efforts. The other father talked about having to be strong for the others, "It is pretty tough on a father and having to be strong for everybody else. I don't worry that much. I mean, I do worry, I don't show my worry and I worry inside." Two of the mothers also mentioned that they needed to do some work in order to make ends meet, but they did not seem to bear the burden of responsibility that the fathers did.

Many of the families talked about the meaning of the illness for their families and for the individuals in their family again at the third interview. One father reflected upon the role of religion and the illness in their emotional lives,

Even though we have a faith in God, and a personal relationship with God, we know by faith certain things, we still have to live this life. We believe there's a lot of potential in this individual, and that there's that element of

life that we don't control, yet we can trust, and do our best and we don't control everything. If we did, we wouldn't have let our little boy have cancer and since he does, we have a process, people pray for us, we don't fear, we don't stay up at night.

The one Hispanic family in the study commented upon the role of their religion in their understanding of the illness experience. According to the mother, "We are believing that God is helping us." The father added, "Since [our child] is getting better every day, we think that He's there helping us. We believe in God, and we believe that He can do a miracle, too."

Families also discussed the meaning of the illness for their future and the future of the child. "We are actually not too worried, because of what the doctor told us. He said that there was a 96 or 97% chance that she would get well. That means that he was almost sure. That's why we're not as worried. If he had said that there was a 50% chance, then we would be more worried." For another family, the uncertainty was more difficult to come to terms with, "The fear is that there's never really an end to it."

In this study families were still in the process of restructuring their reality three months after remission, suggesting that this was an attenuated process that existed independently of medical events such as remission and that families may benefit from continued assessment and intervention in relationship to illness-related issues throughout the illness trajectory. It may be that the uncertainty related to the illness prognosis and survival means that families never really achieve the stable state, but are constantly trying to redefine their reality in the face of uncertainty.

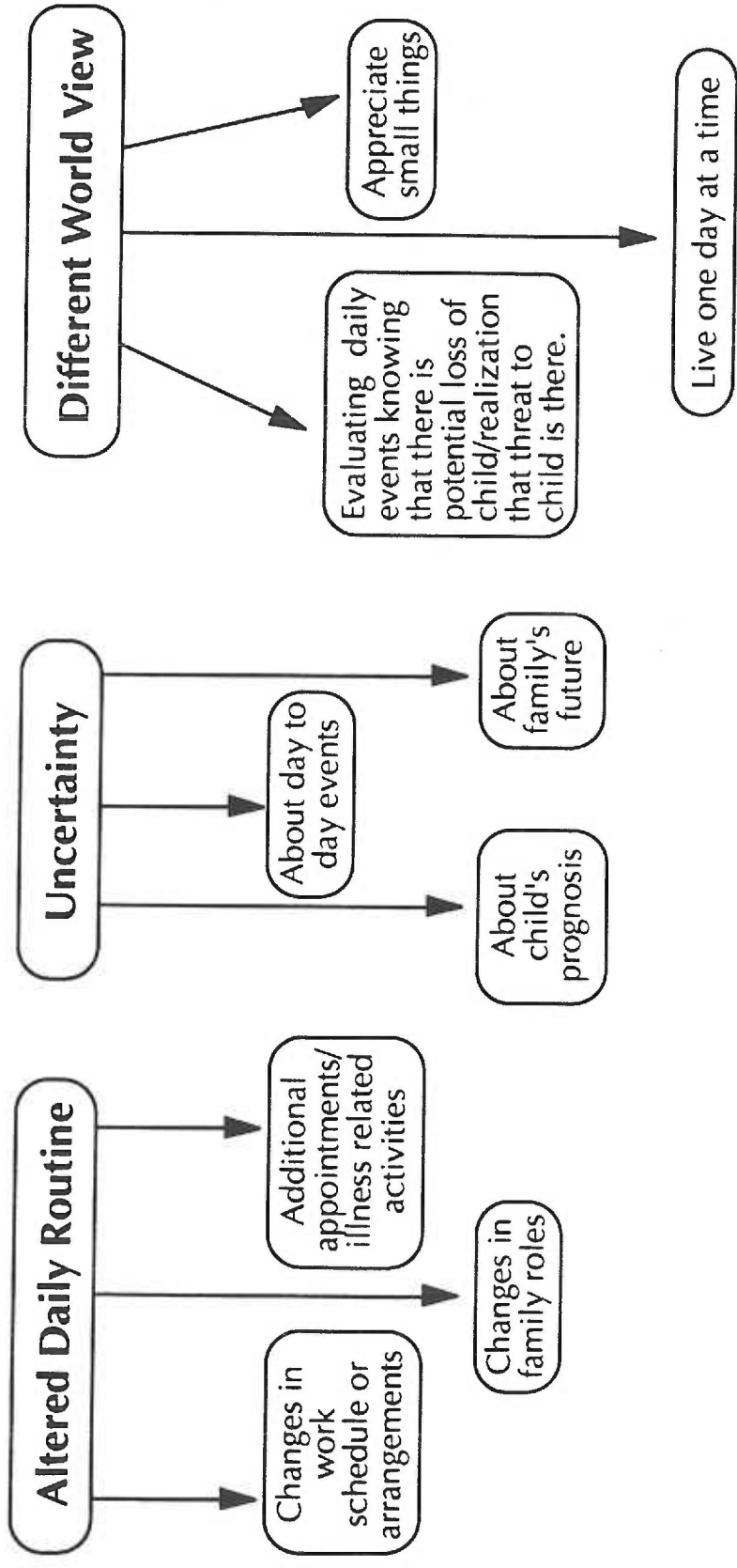
## New Normal

The new normal described by these families was characterized by a return to previous activities, but was marked by a realization that the illness is part of their lives, a new identity for the ill child, and an affirmation of priorities of family closeness and living for the day. A graphic depiction of the concept new normal is shown in figure 6.

Families still discussed the issue of normality at the second interview. One family said it was more normal. Another mother described struggling to make it like normal, "We thought we were getting life back to normal and then when he was so sick. Our emotions were all messed up again and we were scared and uneasy." The father added, "I was trying to, we're trying to get back on our feet. We all want to get there real fast but we just can't. We're doing all right." One had the sense that the illness and its related activities and concerns were also becoming more of the norm. Certainly no one was ready to say that things were *back* to normal.

Normality was the most universally discussed theme at the third interview. For some families, it was described as a "new normal." Their life felt normal now, but it was definitely different from the normal before the illness. In one family the father responded to the question, "Have things returned to normal?" with, "Well, they're getting there sort of." His wife added, "This I just assume is normal now for a couple of years." She added later on in the interview, "An extra sense is there that I think it puts on added things in the day that I have to remember. There are more important things like giving her her medicine. It's scary. I mean there's that extra little thing that I have to worry about." This was

Figure 6.  
New Normal



due in part to the uncertainty related to the illness, "Everything's pretty much unknown anymore", and the continued changes in daily routine which were required for medical treatment.

For other families life was "more normal" now or almost "back to normal." One mother said,

I think it's given us, probably back to normal. Since we have been [home] more and it has not been near as many times as she has had to go up [to the University Hospital] as before. It's not normal. I don't think it'll probably be normal until maybe two years after she is done.

The father added, "It's definitely not our daughter but it is the thing that is going to be normal now for the next sixteen months...which will be a normal for us. That is, it isn't normal by all means." One ill child said, "I've been going to school and stuff and doing everything that I used to do last year and stuff. Nothing's changed with anybody else." His brother said in contrast, "I think there is a little more tension now," to which his father answered, "I think [you] are right. Although I think we are a lot more back to normal." The distinctions between "more normal" and a different normal did not seem to be great as the families expanded upon their definitions of more normal.

One family described their lives as back to normal as family members said, "It's been pretty normal," and, "Back to normal," and "Right now, I think their lives, even his, has just been so normal." However they also told anecdotes which led the researcher to believe that although their life felt normal, it was a different normal than prior to the illness. They described how attention was shifted from the ill child to the sibling when she got the chicken pox, and the ill

child's response to that, which suggested that that was not a normal situation in that family. "You know when she got the chicken pox, we kind of catered to her a little bit and he got kind of a little jealous, saying, 'That's not fair. You guys treat [her] like that, no one cares about me.'" The mother added,

She didn't have to go to school. And he went to bed and said, 'I don't want to go to school.' And I said, 'You have to, you're not sick.' 'Oh no? I don't have leukemia?'...They can just throw it in your face just like anything else.

This was not the same normal as previously because he had not had the illness to use as leverage in his efforts to influence his parents. This family also talked of reevaluated priorities, suggesting that their accepted values and planned activities had taken on a different character.

### Uncertainty

In later interviews, after the diagnosis was known, waiting and not knowing took the form of waiting to see how the child would respond to treatment and the uncertainty that goes with any disease which can have a course of remissions and relapses. The questions now were, would it come back? How will I know if my child has a relapse? When will I be able to quit worrying about a relapse? For all but one family this uncertainty was not as intense an agony as that preceding the diagnosis. There was no crescendo of emotion as there was when the diagnosis conference approached. All but one of the families had implemented strategies that minimized the uncertainty, whittling away at the number of concerns that remained uncertain. It was as if the

uncertainty had become better defined, limited, and was now such that it could be contained and managed without undue distress.

However, the nagging quality of this uncertainty took its toll in a different way. For one mother that agony of not knowing if her child would be cured was just as intensely upsetting as the not knowing before the diagnosis was made final. For this mother, it was intolerable to be told that there was an 85% chance of long term survival. She was singularly distressed that the professionals would not use the word "cure". She said, "If not cure, what then?" This family seemed to have a much harder time reconciling the uncertainty than others. The only apparent difference between this family and others was that they had fewer social and economic resources than any other family. In addition, this is the one family judged by the researcher never to have moved from the limbo phase to the new normal phase. It is hypothesized that this family is a chaotic family who used the uncertainty to drive the chaos which characterized their family dynamics.

#### Altered Daily Routine

There was a wide variety in the degree to which daily routines were altered for families. In addition, changes which seemed substantial to the researcher were minimized by the family members. Work schedules were changed for at least one person in each family in order to accommodate the medical appointments and to care for the child during illness episodes. There was the added burden of remembering to give medications to the ill child. In some families, arranging to take care of all the household tasks meant that siblings had to give some of their free time, which they sometimes did reluctantly. And

for two families there was the necessity to make alternative child care arrangements for the siblings during medical appointments.

### Different World View

Many family members were hesitant to consider what the future might hold. This was related to the fact that the child's condition in the future was uncertain. Some parents talked about how they had plans or dreams for their child's future, but that those plans had to be put on hold or not thought about now, since the future was unknown. One father said,

I try not to think in the future and then thinking about her makes me look into the future. The reason I don't look into the future is because I don't know what's going [to happen]. I would like to preplan destiny and I know I can't do that.

The father who wanted to go to Disney World in the near future rather than wait until enough money had been saved characterized the difficulty many parents had in planning in the future. This inability to plan in the future was related to shifting priorities toward family togetherness and enjoying the present, in that both stemmed from the uncertainty about whether the child would remain in the family circle in the distant future.

In contrast to those parents who were unable to plan in the future were those who maintained their confidence in the future at least enough to feel that resources should be saved for that future time rather than squandering them all in the immediate present. In addition, these parents felt that the child's discipline should be maintained, as that child would need to be prepared to live a normal life in the future. Often a given parent would vacillate between these



two viewpoints, and in one family, there was some disparity between father and mother, with the *carpe diem* philosophy prevailing in that family.

Family members, like the father who wanted to go to Disney World, continued to talk about living for today, about needing to live day to day, because that was all that one could count on.

#### Timing of the Transition

The limbo state began in the pre-diagnostic phase of the illness trajectory. Diagnosis and the announcement of remission also occurred while families were in the limbo state. When the remission interview took place at least two weeks after remission, there was evidence that families had already begun to engage in strategies to reconstruct or redefine reality. Redefining reality did not necessarily go with remission, as there were some families whose child was in remission at diagnosis. Those families had not engaged in the redefining activities at the first interview, but were still experiencing an intense, distressing disruption of their reality. Three months after remission, there was evidence that all but one of the families had entered the new normal phase and were continuing to work on strategies that define this new reality.

The transition to living with childhood cancer was occurring in the midst of ongoing transitions and there was interaction between these ongoing transitions and the transition in question. They had a mutual impact on each other. One example was the family in which there were two older siblings preparing to launch from home. They described the effect of the illness pulling them to remain within the family circle at a time when they felt they should be gaining independence and engaging in activities independent of the family. There was

added friction between father and teens as the father felt the teens should be giving more back to the family because of the illness than the teens felt they could manage while continuing jobs, school, and maintaining relationships with their peers. One of the teenage sons summed up the situation, "Our family was kind of drifting apart as families with teenagers do and then with [his] illness it seems like we are all jammed together really close. And now we are kind of gradually drifting apart. And as we saw that closeness it's kinda like it's harder than it was before."

## DISCUSSION AND IMPLICATIONS

The conceptualization of the family experience of living with childhood cancer as a transition has implications for the process and content of delivering nursing care to families when a child is diagnosed with cancer. In addition, there are questions left unanswered by this research about the transition these families experience. This chapter will discuss the transition to living with childhood cancer and the implications for transition theory, uncertainty theory, the delivery of nursing care to families living with childhood cancer, and future research.

### The Family Transition to Living with Childhood Cancer

#### Childhood Cancer Literature

##### Family Unit Response

The present study is one of a small number of studies to consider data from all family members (Birenbaum, 1987a, 1987b). It is difficult but important to consider multiple viewpoints when doing research on the family. Individual family members have differing perceptions and interpretations of events occurring within the family; therefore, in order to understand the family unit, data from all individuals must be considered. A study that does consider data from all family members has the potential to be less biased than a study that considers data from only one or two family members.

In addition, the present study is one of a few studies which collected prospective data from a point in time close to the diagnosis of the illness (Fife, et al., 1987; Magni, et al., 1983; Magni, Carli, et al., 1986; Magni, Silvestro, et al., 1986; Magni, et al., 1988; Powazek et al., 1980). It is important to collect

prospective data because, as one father commented at the validation visit, “We can’t remember exactly what happened. It’s all a blur.”

The study results suggest an explanation for areas where there have been ambiguous or conflicting results across previous studies. This study found that within the families some salient issues, coping strategies, and family tenor varied from time to time over the course of the illness. The finding that families did differ over time in their mood, coping strategies utilized, and issues of concern may help explain the ambiguous results from earlier studies, where time in relation to illness trajectory events was not specified or addressed. Data from this study indicate that the transition to living with childhood cancer is in part a function of time, although duration or length of time may vary from family to family.

This study corroborates the previous finding that uncertainty related to the illness is a factor in the family when childhood cancer is present (Cohen & Martinson, 1988; Comaroff & Maguire, 1981; Koocher & O’Malley, 1981). In addition, findings from this study suggest that uncertainty is related to the credibility of authority of the professionals treating the child, and that the establishment of the credibility occurs early in the course of the illness, when the parents and other family members are most distraught. The family perception of how credible professionals appeared at the time of diagnosis lasted throughout the 4–5 month period studied here.

This study also supports anecdotal and research reports that the family reorganizes to accomplish the tasks of caring for the ill child as well as for the rest of the family members. In particular, this study found that the proportion of

time spent in work and in child and home care roles was redistributed in families. As reported in the literature (Koch, 1985), some siblings found an increase in their responsibility for caring for the ill child, and, for some families, care for the siblings was shifted to outside the family for greater periods of time than before the illness.

Not all parents reported that the marital relationship was strained by the illness. Some couples in this study described an increase both in tension and in closeness, whereas others commented only on the increased strain. One of the most common marital problems cited by parents was that partners utilized incompatible coping strategies. This incompatibility caused tension, even when the conflict in coping was recognized. These findings are consistent with previous research reports (Cornman, 1988; Lansky, et al., 1978). In only one family, were differing coping styles viewed as complementary and helpful, rather than a source of strain.

Family communication was an issue of concern to families in this study. All but the Hispanic family identified communication within the family as an area of concern which they felt they should address. (It has been reported that in the Hispanic culture family members communicate about illness-related concerns differently among themselves than do Anglos (Spinetta, 1984).) Process, content, and timing of conversations were raised as issues, as was a need for better listening skills among family members. Due to the exploratory nature of the present study, it was not possible to link communication patterns with child or family outcomes.

Cohen (1985) and Spinetta and Deasy-Spinetta (1981) have studied family communication about childhood cancer extensively. Inventories have been developed and tested that measure what these authors consider the salient content areas which should be covered. Content of family communication accomplished by the families in the present study seemed to cover most aspects of the illness as studied and recommended by these authors. In addition, there was a wide variety of affect, intent, and style in communicating illness-related information to children in this study.

#### Response of Parents

The literature has reported that parents' initial reactions to the diagnosis of childhood cancer include shock, guilt (Friedman, 1967; Johnson, et al., 1979), denial, anxiety (Fife, et al., 1987; Kupst & Schulman, 1980; Magni, et al., 1983; Magni, Carli, et al., 1986; Magni, Silvestro, et al., 1986), anger (Friedman, 1967), and grief (Lansky, 1974). Guilt has not been universally seen. The present study also demonstrated those responses to the illness. Kupst and Schulman (1980) found less than 50% of the parents in their sample felt guilty. In this study only one family talked about guilt related to their son's illness, and their guilt was related to not having sought expert medical care sooner to avoid life-threatening complications rather than guilt at having caused the disease.

This study found that parents (and even siblings) were preoccupied with the illness at the time of diagnosis. Unlike previous studies, this preoccupation was not identified as "obsessive-compulsive behavior" (Magni, et al., 1983; Magni, Carli, et al., 1986; Magni, Silvestro, et al., 1986).

None of the parents in this study were so depressed that they sought psychiatric care or were unable to carry on their daily functions. However, there were 2 parents whose reactions suggested a mild depression. A third parent, who appeared to be suffering from a moderate depression, described life before the diagnosis in ways which suggested that the depression had existed prior to the diagnosis. This parent was referred to a mental health professional, but chose not to follow up on the referral. None of the parents were formally evaluated for depression, so no conclusions can be drawn.

Anxiety was prevalent for all parents in this study, a finding which has been documented frequently in the literature (Bozeman, et al., 1955; Fife, et al., 1987; Johnson et al., 1979; Kupst & Schulman, 1980; Powazek, et al., 1980; Van Dongen–Melman & Sanders–Woudstra, 1986). Parents in this study were emphatic that the most anxiety was generated during the time preceding the meeting at which the definitive diagnosis, prognosis and treatment were discussed. The literature has not focused on the intensity of distressing emotion experienced by parents during this period of waiting and not knowing. The findings of the present study suggest that clinical intervention to decrease or manage anxiety and communicate empathy and information is appropriate and warranted at this time.

As the families moved beyond the diagnostic phase and into remission, parents reported that anxiety did decrease (Magni et al. 1983; Powazek, 1980), although there was still a great deal of anxiety, particularly if the child was still in poor condition or experiencing complications of treatment. At this time, as

Magni et al. (1983) found, those parents who had seemed as if they might be depressed still seemed depressed.

Uncertainty remained a strong factor in the meaning of the illness for the lives of these parents, a finding consistent with other studies (Koocher & O'Malley, 1981). Denial, usually in the form of not looking at the future and treating the illness as just another disease, was reported by some of the families 1 month and 4 months after diagnosis. This is consistent with findings of denial by Lansky (1974) and Friedman (1967).

Although other studies have alluded to the fact that childhood cancer impinges on work roles of parents, no study has described the extent to which that occurs. The major impact on work roles was felt by the mothers; 43% of mothers stopped work for some portion of time. Of those, 33% returned to their original job (in the home), 33% started another job (in the home), and 33% remained out of the work force. Eighty-five percent of the mothers reported missing work or rearranging their work schedules for repeated appointments and hospitalizations. All fathers missed some work during the initial diagnostic period, and 72% reported continuing to miss some work or rearrange their work schedule to attend appointments and hospitalizations throughout the study. This is a significant amount of time and attention shifted from the work role to the child care role, in some cases reflecting a shift in behavior to better live out values related to the importance of family.

It is also important to examine the societal supports for shifts in roles. If the workplace was supportive of an increased emphasis on family roles during the transition period, it made a positive difference for families in this study. The



fathers who took on the most care of the ill child were in positions where they could determine to a great extent the hours during which they accomplished their work. Whether or not the families' support networks were supportive of shifts in roles was not clear from the data in this study. The existence of governmental and insurance supports of a shift in the emphasis of work and family care roles was also unclear from the study data.

As part of the child care role, parents found themselves developing their advocacy skills as they asked questions and asserted their child's needs to health care professionals. It is unclear what the implications for this shift in roles are for the health care provider, but this shift is important in understanding the complex changes the family is undergoing as they make the transition to living with childhood cancer.

### III Child Response

Children diagnosed with cancer in this sample initially responded with many of the same reactions as have been documented in the literature such as anxiety (Kupst & Schulman, 1980; Peck, 1979; Spinetta, et al., 1973), anger (Geist, 1979), withdrawal (Kellerman, et al., 1977) and worry and apprehension (Karon & Vernick, 1968). Only one child showed signs of patent depression (Friedman, 1967; Geist, 1979; Hoffman & Futterman, 1971; Peck, 1979). Other children were so ill that it was difficult to distinguish depressive symptoms from the fatigue and malaise due to the illness.

As described in the literature, the illness affected the child's school attendance, and even more so, peer relationships in school (Deasy-Spinetta, 1981). All of the school age children attended school once they were past the

first month or so of treatment. Parents reported that they were doing well academically. Shortly after returning to school, several of the children told of having schoolmates confront them about their appearance or the fact that they might die. This was distressing for the children who reported feeling embarrassed and for the one child who stated he felt "friendless". One child, who was told by a friend that she would die because she had cancer, was frightened and shocked as that was the first she had directly confronted her prognosis. The net result was that for most of the children the return to school had its difficulties.

By the third interview most of the parents believed that their children were adjusting well to the illness. They told stories of their children participating in normal social interactions with their peers, despite an occasional teasing episode. They also described the children as not becoming as upset or anxious about the treatments.

Some of the children were trying to use the illness to manipulate parents. Most of the parents were aware of the attempts to manipulate, and were quick to foil those attempts. One child was still able to test his father, who responded by giving him whatever he wanted. The father's response distressed the siblings and mother. The child, himself, told his father at the third interview that he would like a few limits set for him.

#### Response of Siblings

The siblings in the present study did not exhibit any emotional or physical health problems that demanded attention by a health professional. On the contrary, at least one sibling made a change from having many behavior

problems and poor school performance to assuming responsibility for the care of the ill child and improving grades at school. The question is raised as to whether this child was inappropriately taking parental responsibility, and what will be the potential consequences for his subsequent development. This child and several others however gave indications that they were sad and concerned with their sibling's illness.

In this study the well siblings, regardless of age, seemed to be unable to express themselves clearly to their parents, and parents were unable to interpret their signals of distress and concern. This seemed to be due to parental lack of knowledge of age appropriate responses to illness-related concerns or to the child's reluctance to talk to the parent. For example one set of parents commented on one daughter who did not seem to be concerned about her brother's illness. In the interviews, this child's intensity when discussing her brother's illness suggested that she was very concerned. How this communication problem will affect these families, and specifically the children, remains to be seen and is a topic for further exploration.

It has been reported that parents are not emotionally available to the siblings throughout the course of the illness (Maguire, 1983; Sourkes, 1980; Tietz et al., 1977). In this study, there was variation in how available parents were to the siblings. Most parents reported being concerned about siblings' response to the illness; they made efforts to include siblings in discussions about the illness and to make time to attend to their special needs. Many parents also reported that they realized more should be done for the siblings, but that they did not have the time, energy or ability to do so. Two families, while attending

to the everyday needs of the siblings, did not believe that the siblings would understand the illness and would worry needlessly or would spread misinformation. These parents chose not to discuss the illness with the children, hence the children had no recourse with their parents to air concerns about the illness. There were not sufficient data from this study to suggest or refute a relationship between family communication or family functioning and successful adaptation of siblings as has been proposed in prior research (Birenbaum, 1987b; Deasy-Spinetta, 1981).

As with the siblings in Kramer's study (1984), data from siblings and parents suggested that siblings experienced anxiety, isolation, and worry. They also identified positive aspects of the illness, including increased family closeness, a deeper appreciation for family members, and more of a sense of responsibility for the ill child. In contrast to the Kramer study, siblings in the present study did not express anger at the illness. Some of the older teenagers did express anger at the parents' response to the illness, but they were sensitive enough to differentiate the source of their anger.

In two families, sibling subsystems were strong and rallied around the ill child (the youngest in both cases). It is uncertain whether these sibling subsystems were as strong prior to the onset of the illness or whether the siblings became cohesive because of the illness. Parental and sibling descriptions of the sibling subsystems prior to the illness suggest that the sibling subsystems were cohesive prior to the illness, and that the illness served to strengthen the bonds that tied the siblings together.

### Transition Theory

This study described the transition experience of families as they constructed a new family normal in response to the trigger event of the diagnosis of childhood cancer with a favorable prognosis. Family members described the strategies used to reconstruct the family reality as they progressed through the transition: reorganizing roles, evaluating and shifting priorities, managing the flow of information within the family and between family and the surrounding context, and assigning meaning to the event. It is possible that many of these strategies are used by families in other transition situations; only one author has discussed family transitions to date (Rapoport, 1963).

Initially the diagnosis was experienced as a crisis. However, by the third interview, families generally were beyond the crisis phase and deeply immersed in the process of molding the new way in which they carried out their lives. This suggests that the transition process lasts longer than the crisis. In the case of the transition to living with childhood cancer, the diagnosis is perceived and reacted to as a crisis and serves as the trigger point of the transition.

The phases of transition families described were similar to those described in individual transitions in several ways. Individual transitions have been described as change in role expectations (Allen & van de Vliert, 1984), change requiring reorganization of emotional and relational arrangements (Weiss, 1976), and change requiring different modes of interaction with interpersonal and sociocultural aspects of the environment (Wapner, 1981). Similar to these characteristics of individual transitions, the scope of the family transition described in this study included reorganization of the role structure of the

family, redefinition of salient meanings and values for the family, and change in the ways in which family members related to each other and to parts of the larger community.

The process of the transition described in this study was consistent with Allen and van de Vliert's (1984) work. Allen and van de Vliert described a transition as a reaction to strain which consisted of cognitive, affective and behavioral responses. Although Burr (1972) postulated that the process of transition is not necessarily tumultuous, for these families and for the individual family members, it was fraught with turmoil and psychological distress. These families experienced the disconnectedness described by Chick & Meleis (1986) in that they realized that things which had previously seemed important no longer were and they had great difficulty thinking about the future. In addition, parents talked about the unrealness of their situation, similar to Bridges' (1980) description of the transition process.

The transition was not completed in the 3–5 months of the study. Since all families were still in the process of redefining the new reality at the last interview, it is not possible to compare the outcomes of the transition process with those described in the literature. In addition, the question of whether the transition always involves movement toward a higher or more complex level of functioning is difficult to comment on since there was no baseline level of functioning with which to compare the study families. Indeed, families must be recruited for studies of transition such as this one after the crisis occurs, due to the nature of the phenomenon. It may be impossible to accurately compare

the post-transition level of functioning with the pre-transition level of functioning.

### Uncertainty Theory

Uncertainty has been defined as “the inability to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately structure or categorize an event because of lack of sufficient cues. Uncertainty occurs in a situation in which the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes accurately,” (Mishel, 1984, 1988). The theory of uncertainty proposed by Mishel (1988) posits that uncertainty is inherently neither positive nor negative, but that because of the ambiguity of stimuli, they may be interpreted either way. When uncertainty is appraised as negative or harmful, coping strategies to reduce uncertainty are implemented. In contrast, when uncertainty is appraised as positive or helpful, then coping strategies are implemented that will preserve the uncertainty of the situation. In illness, factors influencing the perception of uncertainty include symptom patterns, event familiarity, and event congruity. These factors are modified by individuals’ cognitive capacities and information processing abilities. In addition, factors such as the credibility of authorities, social support and education influence the perception of uncertainty.

Uncertainty theory is relevant to families of children with cancer as they move through the transition to living with the illness. Certainly the study families were confronted with a situation in which it was difficult to assign values. For example, was it good that a child had a 75% chance of long term survival or bad that a child had a 25% chance of an early demise? In this study

parents talked about the lack of sufficient cues: "How do you expect me to remember? I don't know what the heck I'm doing, I've never done this before. If we ask questions, it's because we don't know." Events had multiple and ambiguous meanings. For example, one mother talked about finding out her son was in remission, "How can he stay in remission? When his body is in such awful shape and his counts were terribly low and his gums were pure white again and he was a mess. And he was just lifeless. And I thought, there's just no way that he's in remission. But it was encouraging to know that he had stayed in remission through all that."

Determining the meaning of the illness was difficult. Family members attached many meanings to the illness, but most of these meanings were transitory and in the process of being developed and remolded as the events of the illness unfolded. After a month most parents believed that the existential meaning was yet to be revealed to them, "Sometimes I do wonder what it is all about? I mean, what is this great big lesson that I am going to learn?"

All but one of the families in the study utilized strategies to minimize uncertainty. Often these strategies related to gaining and controlling information. The one family who did use strategies that perpetuated uncertainty was the only family that struggled with whether the physician knew all that there was to know about their child's illness. This family, like the other families, used information seeking and control strategies, but family members also questioned the credibility, accuracy, and underlying meaning of every piece of information. When there was any room for an interpretation of uncertainty in



any information or event, this family was quick to focus on the interpretation of uncertainty.

More specific to childhood cancer, Cohen and Martinson (1988) looked at the effect of uncertainty in families who had a child diagnosed with cancer. They described phases to the uncertainty; this also was evident in the present study. Cohen and Martinson's first phase was diagnostic uncertainty which created a sense of urgency for the parents. In addition parents exhibited hypervigilance for signs of any health problems. This phase was followed by chronic uncertainty in which the hypervigilance continued. When a child died, the hypervigilance was often transferred to a sibling.

Also similar to the present study, Cohen and Martinson (1988) found the parents to be vulnerable as a result of the uncertainty of the illness. In contrast with the present study, their study found that cognitive appraisal was impaired as a result of the uncertainty. This impairment was particularly in regard to determining when symptoms of the ill child required medical attention. In cases where the child had died, the Cohen study found that this impaired appraisal effect was transferred to the siblings. In the present study, cognitive appraisal did not appear to be impaired. Indeed, parents became more alert to possible threats to all of the children. For the most part, parents did not engage in seeking unnecessary medical care. Differences between these two studies may be due to interpretation of the parental behaviors. One mother added further insight by suggesting that the reason for seeking care which would not have been sought previously was that she felt unable to handle the ordinary problems with the demands of the illness: "I don't think twice about taking them

to the doctor if they're sicker than I can take care of and that's minimal now." Difficulty interpreting symptoms seemed to be more related to changes in the child's condition and the subsequent ambiguity of the symptoms than to deficiencies in the parents' ability to appraise the situation.

It is interesting to note that another qualitative study of parents and siblings found that the appraisal process of parents changed over time (Brett & Davies, 1988). In the Brett and Davies study, parents initially appraised the illness with alarm, due to the interpretation that survival was impossible. As time passed and the parents realized that survival might be possible, they went through a vigilant phase (similar to the vigilance of parents in the present study). As more time progressed and parents believed that survival was probable but not certain, the vigilance became more relaxed. The Brett and Davies study also did not conclude that parents were deficient in their appraisal capacities.

One of the hallmarks of treatment of childhood cancer seems to be that the side effects and complications are relatively unpredictable. In addition, the child's physical status often changes, so that signs that were useful predictors prior to the illness are no longer valid predictors. One mother stated, "The scariest part for me is not using the typical types of situations. Before all this happened, if he was running a 101 temperature, he was a pretty sick little boy. And when we put him in the hospital he had 103.4 and he's feeling great. He doesn't have any signs of being sick or really exhausted or whatever and it's kind of hard for me to judge. I've asked him if he can feel something coming on. Is he a good judge for himself? And he's not. And that's scary."

### Implications for the Delivery of Nursing Care

This study has implications for the delivery of family nursing care at all phases of the transition. In general, nursing is prepared to care for families when health care delivery systems are structured to allow time and other resources for this specialized care. Family nursing is more than caring for the patient in the context of family and has as its goal the health of the family unit rather than the health of a single individual. Therefore, nursing of families in the transition to living with childhood cancer should have as its focus the entire family. While the nurse may intervene with only one or a select subset of family members, the goal is always family oriented.

Nurses are prepared for family nursing both at the generalist and specialist levels. There have been different combinations and multiple disciplinary teams that have provided family centered care to families of children with cancer (Friedman, 1967; Gogan, et al., 1977; Hoffman & Futterman, 1971). Findings from the present study do not refute the efficacy of these approaches, but rather suggest that families, and therefore the ill child, may benefit from a family centered nursing care model.

In addition, this section will consider implications for nursing care specifically related to the family's waiting and not knowing, evaluating and shifting priorities, managing the flow of information, and managing the therapeutic regimen.

#### Clinical Implications – Limbo Phase

The period of waiting and not knowing described in this study is clinically significant for nursing. In the study parents perceived that the intensity and

agony of this period for families were underestimated or unacknowledged by many health care providers. In addition, a common perception was that professionals did not relate to families in a personal way. This added to the nightmare quality of the experience for the family. Reasons for an impersonal stance on the part of health care professionals may include self-protection, ignorance of the significance of the diagnosis for parents and families, the routinization of the diagnosis or a mix of these. (It should be noted that several families commented that the nurses on the inpatient ward were "there for them", willing to listen, and the families found this helpful: "I think just the kindness and being there, a shoulder or crutch or something is the greatest thing that they could do at all.")

Regardless of why the health care professionals responded as they did, the family's perception of the credible authority of care providers at this time had an effect on their later integration of the illness experience into their lives. Less credible authority was associated with increased uncertainty and distress as much as 5 months post diagnosis. The families themselves stated that they wanted full honesty at all steps of the way. A commonly shared assumption among health care professionals is that they should not give information until all test results are known because parents do not need to know or worry about the unlikely worst options (Ekert, 1983). The data from these families suggest that they did know about or imagined the worst possibilities, and, as one teenage son stated, they wanted to know the worst that could happen up front: "The doctors were real straightforward when they told us everything. And I think

that's real important. They told us the facts, told us the good and the bad side. They're telling us the worst but they hope for the best."

Intervening during the waiting and not knowing period prior to diagnosis became difficult, because there generally was a fair amount of lag time between when the child was first seen and when all tests were completed, all the necessary information was gathered and all the data were analyzed. However, alerting families to the difficulty of this time period, suggesting some coping strategies that have worked with other families, eg. talking with other parents of children with cancer, acknowledging their distress, and being available both physically and emotionally to address their concerns are viable intervention strategies to test.

### Clinical Implications – Reconstructing Reality

#### Evaluating and Shifting Priorities

The evaluation and shifting of priorities in life seems to be a phenomenon of chronicity; for example it may not appear after the sudden, unexpected death of a child but not infrequently does after a prolonged illness (Knapp, 1986).

One mother explained this phenomenon in terms of getting a second chance:

And I feel fortunate. Three children were killed here in [our hometown], in an auto accident and I felt so lucky that I had a second chance where they didn't at all, you know, and if you look at it that way. Gosh, I'm real good at that now. You know, some people don't have any other chance, they're gone and that's it.

Knowledge of this difference in how families react to the two different types of tragedies can lead health care professionals to intervene accordingly with the

two groups. It is necessary first, however, to test as an intervention the support of the process of evaluating and shifting of priorities as an effective coping strategy for families in the face of chronic and potentially fatal childhood illness.

One possible way of supporting families as they evaluate their priorities is to assist families in clarifying long- and short-term goals. They can also be helped to identify individual priority conflicts and resolve them, so that families are working together toward common goals. Families can be helped to relate these goals to their underlying values by questioning how those values contribute to the goals or how the goals are an expression of the values. Finally, helpers can assist families in identifying ways of achieving the goals and living out their expressed values.

#### Managing the Flow of Information

Since information management involves such a wide range of tasks for families, there are several implications for how health care professionals can aid parents in gathering, processing, and distributing information about the child's illness. Although parents do get advice on sharing the information with children, information about the range of appropriate responses at different developmental levels may help parents to further understand and appreciate the meaning of the children's responses to finding out about the illness and its implications. Helpers should be aware of parental value systems in relation to communication with their children about the illness and give parents guidance with those values in mind.

It was of interest to note the patterns of communication with the researcher in the families across the interviews. In most families, the dominant

communicator tended to be the same across interviews. This varied between the mother and father for all families. It was interesting also to hear comments from various family members about how different persons usually communicated and then to see how they actually did with the researcher. Of particular note was one family in which both mother and father separately told the researcher that one of the children was very shy and probably would not talk much. Of the three children in the family, this child had the most to say and seemed to have the most urgent need to communicate some of her concerns. In another family, after nearly 45 minutes of talking, the father commented on the trouble he had communicating with his wife, and people in general, and how unusual it was that he was talking this much. When the interview was scheduled with yet another family, the mother stated that her children would probably not say much, that they were pretty private about sharing their emotions. The investigator found the interviews with those children to be among the more informative of the children interviews, and the children in some ways were more open about their emotions than the parents. One of the boys choked up during his interview. The mother in contrast was much less emotional about her interview, laughing much of the time, and not divulging the emotional content which the children had. The question was raised by the researcher that the mother might have been talking about herself more than her children.

Anticipatory guidance is requested by the parents. In the realm of information management, parents need to know about the expected responses of parents, siblings and ill children. Parents need to know that depression may

occur in any family member. They also need to know how to detect depression in children.

Guidance in the area of reorganization of roles might also be helpful, particularly with respect to both parents putting more emphasis on the home roles rather than work roles. In addition, parents must be alerted to the possibility and implications of siblings taking on inappropriate child care responsibilities for the ill child.

Finally, parents need to know about the effect of differing coping styles on the marital relationship, as well as how to recognize those effects in their own relationship. They need to know the role of time in the transition process, that a new normal is eventually reconstructed.

#### Managing the Therapeutic Regimen

Parents in this study indicated that they would have liked nurses to let them know what sorts of responses, both physical and emotional, they can expect from the ill child. Therefore, nurses should take additional time to explain repeatedly what can be expected at each medical phase of the illness trajectory.

The single other most difficult task for parents is managing appointments and communications between a variety of health care providers. Nurses are already doing a lot of work in this area. One strategy, that has been tried in some institutions, is a case management approach.

#### Timing of the Transition – Clinical Implications

The longitudinal nature of this family transition suggests that family assessment and intervention should be planned throughout the illness trajectory, not just at the emotionally intense times of diagnosis and relapse. There is



evidence in the data that the illness is interrelated with family issues throughout the remission and into the maintenance phases of the illness trajectory. At the validation visit, one set of parents stated that they did not begin to really deal with the emotional issues until their child completed the prescribed 6 months of chemotherapy.

Family communication was another issue which spanned the entire time of the study. Most families indicated that they continued to make efforts to communicate about the illness and new developments throughout the 4–5 month period of the study. However, family members also indicated that sometimes they wanted guidance in communicating about the illness. One father, after the third interview when several family members shared feelings not shared before, seemed disappointed that there would be no more interviews, and commented that it was too bad that the researcher could not do this every couple of months.

Additionally, the intensity of the experience for family members suggests that they need professionals who are specially prepared for caring for families making the transition. This preparation includes knowledge of family theory, family intervention, when and to whom to refer for family therapy, illness trajectory information, family communication skills including the abilities of being present, empathizing, and validating the family's experience of the illness, and the ability to spend time and emotional energy with family members. Many parents commented on the helpfulness of the nurses on the hospital unit, nurses who had been there to listen and who "showed a little human kindness." For most families, this form of intervention was available for 5 days to a week

following diagnosis before they were discharged to home. After discharge the children were medically managed at the University clinic and/or by the local physician. For the families in the study there was no professional who was prepared for and responsible for the task of being present and available for comprehensive family assessment and intervention for every family. The physicians felt that it was their responsibility to look out for the families: as one physician commented, "We really do total patient care here."

#### Implications for Research

There are two types of research suggested by this study, research to answer theoretical questions and research to evaluate clinical interventions. The theoretical questions that arise focus on how the families continue to adapt to living with childhood cancer throughout the illness trajectory. What happens when the child completes treatment? What happens if the child relapses? Goes into remission again? Undergoes a bone marrow transplant? What is the effect of time versus the occurrence of trajectory events in the transition process? In addition, the question arises as to whether the transition is different for children who do have a good prognosis as opposed to those for whom it is almost certain that death will be the outcome. Will the findings of this study hold up with larger numbers of families at sites other than the one sampled? All of these questions should be explored through qualitative methods initially, so that theory can be generated. Specifically, the transition needs to be investigated for a longer time period with a larger sample. In addition, different illness trajectories should be sampled so that effects of trajectory versus time can be explored.

Variables which will affect the family's movement through the transition were also suggested by this study. For example, further study of aspects of communication (such as amount, content, tone and age appropriateness) and their effects on the family's transition would be a significant area of research.

In addition, clinical interventions have been suggested by this study which require testing. Outcomes that should be evaluated for these interventions include family functioning, individual adaptation by family members and medical outcomes such as complication rates and compliance with treatment. Not only is it important to document the effects of family intervention on family variables, but since the health care system is focused on the health problems of the child with cancer, it will be necessary to document the effects of the family intervention on the management and outcome of the illness in order to justify the expenditures for family intervention.

#### Methodological Implications

##### Family Research in a Sensitive Area

It has long been considered difficult to enter the homes of families immediately after a crisis such as the diagnosis of childhood cancer. The only two known studies to do so were conducted in recent years (Fife, et al., 1987; Powezek, et al., 1980). In addition, there are ethical concerns about whether families can be asked to participate in research during this time due to their vulnerability. Families who participated in the present study seemed to think that the researcher's intrusion was something they could handle. Four families did not share this view and expressed it to the researcher in their refusal to participate in the study. Although families were vulnerable at the time of the

study, they did have the ability to refuse participation when they felt it was too much. This may have been made possible by the fact that the researcher was not involved in the medical or nursing care these families received, so there was no confusion about their required participation and no fear that non-participation might influence the care their child received. The experience of this study and others (Fife, et al. , 1987; Powazek, et al., 1980) suggests that families can tolerate research of psychosocial aspects of the illness at the time of diagnosis. The importance of the experiences immediately surrounding diagnosis in forming later responses suggests that this is a time in the family's experience which should be investigated.

#### Fathers Versus Mothers

Data from some fathers tended to be more terse, matter of fact, and less emotionally laden. However, in 3 of the families, the fathers were quite reflective and willing to share their emotional responses. The more expressive fathers were varied in their socioeconomic status. The stereotypical roles of husband as the practical worker and wife as the emotional worker in the family did not hold for the entire sample, although it did for some families. The fact that the researcher was a female undoubtedly influenced the way in which informants responded to the questions. However, due to the comparable quality of data from men and women informants, it was thought that individual personalities of the participants as well as the sensitivity and interview skill of the researcher had an equal or greater influence on the quality of data.

### Quality of Sibling Data

Questions arise in the literature about the reliability and validity of data from children. Difficulties in interviewing children stem from the different repertoire of skills which they use to express themselves. The result is that often adults have difficulty understanding children in regard to complex and emotional topics. In addition, there is the question of how children respond emotionally to an unknown adult asking them difficult questions about private matters, and how that affects the responses that they give.

In many instances young children in this study did give responses which, although not as detailed and complex as their parents gave, were consistent with what parents told the investigator. At times children said things which, together with their non-verbal behavior, shed new light on issues within the family. For example, in one family, the mother reported that one of the siblings was "in his own world" and not too much affected by the illness. When this sibling talked with the investigator, some very intense worries were shared, as well as the perception that the sibling had made some sacrifices to care for the ill child. On the other hand, there were two instances when children were so shy or frightened that they did not want to talk at all. The researcher did not pressure these children to participate. By the last interview, however, all children were eager to participate and share their stories. Perhaps this was due to their familiarity with the researcher and to the interview process. It is also possible that the ill child's physical condition and current coping with the illness was such at later interviews that it was more comfortable for them to talk then.

The older children and adolescents were able to give much more detailed responses than the younger children and were able to attend to and contribute to the kitchen table discussions. It was difficult for younger children to sit and track the conversation while their parents were talking during the family interview. The younger children would occasionally introduce topics of their own in the middle of other topics, or they would be unable to respond to questions directed at them because they were not paying attention, did not understand the question or did not want to answer. Several authors have recommended using projective techniques with younger children as a way of helping them to express themselves (Spinetta, et al., 1973, 1974; Walker, 1988). Although this study found that children can respond to questions and can give information in an interview situation, it was believed that additional techniques, such as projective drawings or play interviews, might have added to the quality and quantity of data from the younger siblings.

#### Interview Setting

Interviews took place in several different places during this study. Interviews most often occurred in the home, in a bedroom or other private room. In one family, the most private spot the family would consent for interviews to take place was in the kitchen while remaining family members were in the adjoining living room. A couple of families were interviewed in a small conference room in the clinic. For two of these families, the data obtained in this manner were both extensive and filled with emotional expression of intense issues. In another family, the father only was interviewed in the clinic for the first interview. In this interview, he was terse, although not

unfriendly, and reluctant to discuss his emotions. Later interviews with this father, which were in the home, yielded more emotional information and more detailed answers, although he still was somewhat guarded in his responses. It is unknown whether the clinic setting had the effect of minimizing the emotional feeling which he felt could be expressed, or whether it was part of his general way of relating to people and that he tended to be business like, particularly with strangers.

Use of the phone and an audio recorder with two teenage siblings who were unable to schedule time with the researcher worked well technically. The answers were consistent with parent data and subsequent in person interviews. However, the data were not as detailed or emotion laden as in later interviews. The question again arises whether this was due to the strangeness of the researcher, or to the phone interview being less “personal” and therefore less conducive to the disclosure of personal data. The researcher believes that particularly in the situation of not having met the researcher personally, the phone interview situation does make for a less comfortable atmosphere. In addition, the researcher found that the lack of nonverbal cues made it difficult to interpret responses and to choose probes for follow-up.

#### Interviewing Families

Due to the large size of the study families, the issue of how to manage a large number of individual interviews within a single family visit arose. Several hours of emotional interviews meant that researcher fatigue was a concern, and that persons who were interviewed first may have had a different experience than those who were interviewed later. Also, by the time the fourth or fifth

person told the story, the researcher could anticipate many of the comments before they were given, which may have influenced to some degree the direction of the questions and probes. In one family this difficulty was handled by switching the order in which family members interviewed at the next interview time. However, this was serendipitous and was not done for other families, as it was not realized until much later that switching order had changed who were the most expansive informants in that family. In addition, this may have been a response unique to that family.

#### Kitchen Table Interviews

The kitchen table or family interview is a relatively new data collection technique for research although it has long been used in family therapy. The family interview worked well in most of the study families. Those that worked for were characterized by older children and openness. In the families with young children there was a tendency for the parents to dominate the conversation and the children to add a few comments only when addressed by the researcher. Within these families also there was a varied amount of inclusion of the children by the parents. In one of the families it seemed as if the parents were reluctant to give as candid and emotion laden a response in front of the children as they had in private. These interactions gave a different type of data to the researcher than verbal information given by the family members. Instead of facts and feelings, they gave the researcher information about the patterns of communication within the family and the value placed on the contribution of the children.



In addition, the family response to the kitchen table interview seemed to be related to the degree to which the families practiced open communication within the family. For families who valued open communication among all family members and who tried to communicate openly on a regular basis, the communication among family members during the interview was interactive with little prompting from the researcher. For families who were not accustomed to this kind of communication, the process was a little more cumbersome, with considerable direction and questioning from the researcher. These family members found it difficult to share their feelings with other family members and difficult to encourage and acknowledge other family members in their communication of deep feelings. Certainly the data were of a different nature than the data from individual interviews, and this researcher believes that individual and family interviews are both sources of rich data. When looking for family process and family meaning information both are necessary and complementary sources of data.

#### Summary

The purpose of this qualitative study was to describe, from the family's point of view, the family transition to living with childhood cancer. The major research question of this study was: What is the experience of families when a child is diagnosed with cancer with a favorable prognosis. Cancer with a favorable prognosis is defined to be any subtype of cancer for which the long-term survival rate was greater than 60%.

The extensive body of literature about the psychosocial effects of childhood cancer has described the responses of every family member as an individual.

However, few studies have described the period immediately surrounding the diagnosis of childhood cancer prospectively. In addition, few studies have utilized data from all family members. No study to date has been an exploratory study that takes into account all of many variables which have been examined in relationship to the psychosocial responses of the family to childhood cancer.

This study used a transition perspective to examine the family's response to the diagnosis of cancer in one of the children. This perspective assumes that a crisis or trigger event throws the individual into a period of disruption, which causes the reconstruction of a new order, or new organization of life patterns. In addition, symbolic interaction and systems theory informed the conceptual model of this study.

The convenience sample for this descriptive, longitudinal, prospective study was drawn from a northwestern health sciences university pediatric oncology clinic. Forty members of 7 families of children recently diagnosed with cancer with a favorable prognosis participated. Each family had at least one child 5 years old or older and lived within driving distance of the university.

Data collection consisted of three tape-recorded, semi-structured interviews with family members in the home. During the first 2 interviews, all family members over the age of 5 were interviewed individually. During the first interview, one or both of the parents together completed a demographic questionnaire. The third interview was a group interview with the entire family together. Interviews occurred at the time of diagnosis, at the time the child

went into remission, and 3 months post remission. A modified grounded theory approach to data collection and analysis was used.

The major finding was a model of the family transition in response to the diagnosis of childhood cancer. This transition was characterized by a fracturing of reality at the realization of the malignant nature of the illness, a period of limbo following the diagnosis, the utilization of strategies to reconstruct reality, and a "new normal" for the family. The transition process continued for the 4–5 month course of the study and, in all families, extended beyond the study period.

The limbo phase was characterized by a period of waiting and not knowing which was followed by the emotional reaction when the diagnosis was made. From this disruption, families utilized strategies such as reorganizing roles within the family, evaluating and shifting of priorities, managing the flow of information, assigning meaning to the illness experience, and managing the therapeutic regimen to construct a new normal. The new normal was characterized by an altered daily routine, uncertainty, and a new world view.

The findings are consistent with much of the previous literature on psychosocial responses to childhood cancer. In some cases the findings differed, and in other cases, divergent findings in the literature could be explained by the changing responses, coping strategies utilized, and family tenor of the families in the present study. Implications of this study for clinical practice include the need for continued nursing involvement with families throughout the transition time, extending beyond medical remission. In

addition the findings suggest that family-focused nursing would be helpful for the families.

Factors limiting generalizability of the findings include the small sample size, single site, and the shortness of time families were followed. Implications for nursing practice include the family's need for continued nursing involvement throughout the illness trajectory, past medically defined remission and a need for nursing care to be family focused. Research implications include further exploration of the transition over a longer period of time, with a variety of illness trajectories and a larger sample. Innovative interventions and their effect on psychosocial and medical outcomes should then be tested. Continued exploration of the experience families have when a child is diagnosed with cancer will assist nurses in providing care which optimizes health and development for families with a child with cancer.

## References

- Aguilera, D. C., & Messick, J. M. (1982). Crisis intervention: Theory and methodology (4th Ed.). St. Louis: Mosby.
- Allen, V. L., & van de Vliert, E. (1984). A role theoretical perspective on transitional processes. In V. L. Allen, & E. v. d. Vliert (Eds.), Role transitions: Explorations and explanations (pp. 3-18). New York: Plenum Press.
- American Cancer Society. (1985). Cancer Statistics 1985. New York: Author.
- Anderson, J. M. (1981). The social construction of illness experience: Families with a chronically ill child. Journal of Advanced Nursing, *6*, 427-434.
- Baider, L., & De-Nour, A. K. (1989). Group therapy with adolescent cancer patients. Journal of Adolescent Health Care, *10*, 35-38.
- Bakke, K., & Pomietto, M. (1986). Family care when a child has late stage cancer: A research review. Oncology Nursing Forum, *13*(6), 71-76.
- Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science. Advances in Nursing Science, *8*, 1-14.
- Benner, P. & Wrubel, J. (1989). The primacy of caring. Menlo Park, CA: Addison Wesley.
- Binger, C. M., Ablin, A. R., Feuerstein, R. C., Kushner, J. H., Zoger, S., & Mikkelsen, C. (1969). Childhood leukemia: Emotional impact on patient and family. New England Journal of Medicine, *280*, 414-418.
- Birenbaum, L. K. (1987a). Description of family communication about chronic illness in children with cancer. Unpublished doctoral dissertation, University of Washington, Seattle.
- Birenbaum, L. K. (1987b). Effect of family nursing on sibling response to dying. (Division of Nursing Grants 1R01 NU 00912 and 1R01 NU 00912-02S). Portland, OR: Oregon Health Sciences University.
- Birenbaum, L. K. (1989). The relationship between parent-siblings' communication and siblings' coping with death experience. Journal of the Association of Pediatric Oncology Nurses, *6*(2), 26-27.
- Blumer, H. (1969). Symbolic interactionism: Perspective and method. Englewood Cliffs, NJ: Prentice-Hall.

- Bozeman, M. F., Orbach, C. E., & Sutherland, A. M. (1955). Psychological impact of cancer and its treatment III. The adaptation of mothers to the threatened loss of their children through leukemia: Part 1. Cancer, 8, 1-19.
- Brett, K. M., & Davies, E. M. B. (1988). "What does it mean?" Sibling and parental appraisals of childhood leukemia. Cancer Nursing, 11, 329-338.
- Bridges, W. (1980). Transitions. Reading, MA: Addison-Wesley.
- Broderick, C., & Smith, J. (1979). The general systems approach to the family. In W. R. Burr, R. Hill, F. I. Nye, & I. L. Reiss (Eds.), Contemporary theories about the family (pp. 112-129). New York: The Free Press.
- Burr, W. R. (1972). Role transitions: A reformulation of theory. Journal of Marriage and the Family, 34, 407-416.
- Byrne, J., Fears, T. R., Steinhorn, S. C., Mulvihill, J. J., Connelly, R. R., Austin, D. F., Holmes, G. F., Holmes, F. F., Latourette, H. B., Teta, J., Strong, L. C., & Myers, M. H. (1989). Marriage and divorce after childhood and adolescent cancer. Journal of the American Medical Association, 262, 2693-2699.
- Cairns, N. U., Clark, G. M., Smith, S. D., & Lansky, S. B. (1979). Adaptation of siblings to childhood malignancy. Journal of Pediatrics, 95, 484-487.
- Chen, Y. C. (1988). A Taoist model for human caring: The lived experiences and caring needs of mothers with children suffering from cancer in Taiwan. Doctoral Dissertation, University of Colorado Health Sciences Center, Denver, Colorado. (From Dissertation Abstracts International, 49(8), 3101B).
- Chick, N., & Meleis, A. I. (1986). Transitions: A nursing concern. In P. L. Chinn (Ed.), Nursing research methodology issues and implementations (pp. 237-257). Rockville, MD: Aspen.
- Chodhoff, P., Friedman, S., & Hamburg, D. A. (1964). Stresses, defenses and coping behavior: Observations in parents of children with malignant disease. American Journal of Psychiatry, 120, 743-749.
- Clarke, L. (1986). The transition from "on treatment" to "off treatment": A study of families of a child with cancer. Unpublished paper, Oregon Health Sciences University, School of Nursing, Portland, OR.
- Clements, I. W. (1983). Crisis theory. In I. W. Clements, & F. B. Roberts (Eds.), Family health: A theoretical approach to nursing care (pp. 145-156). New York: Wiley and Sons.

- Coccia, P. F. (1983). Development and preliminary findings of Children's Cancer Study Group protocols (161, 162 and 163) for low-, average- and high-risk acute lymphoblastic leukemia in children. In S. B. Murphy, & J. R. Gilbert (Eds.), Leukemia research: Advances in cell biology and treatment (pp. 241–250). Elsevier Science.
- Cohen, D. S. (1985). Pediatric cancer: Predicting sibling adjustment. Unpublished doctoral dissertation, University of Washington, Seattle.
- Cohen, M. H., & Martinson, I. M. (1988). Chronic uncertainty: Its effect on parental appraisal of a child's health. Journal of Pediatric Nursing, 3, 89–96.
- Comaroff, J., & Maguire, P. (1981). Ambiguity and the search for meaning: Childhood leukemia and the search for meaning in the modern clinical context. Social Science and Medicine, 15B, 115–123.
- Corbin, J. (1986a). Coding, writing memos, and diagramming. In W. C. Chenitz, & J. M. Swanson (Eds.), From practice to grounded theory: Qualitative research in nursing (pp. 102–120). Menlo Park, CA: Addison–Wesley.
- Corbin, J. (1986b). Qualitative data analysis for grounded theory. In W. C. Chenitz, & J. S. Swanson (Eds.), From practice to grounded theory: Qualitative research in nursing (pp. 91–101). Menlo Park, CA: Addison–Wesley.
- Cornman, B. J. (1988). Impact of childhood cancer on the family. Doctoral Dissertation, University of Washington, Seattle. (From Dissertation Abstracts International, 49(7), 1976A).
- Cunningham, B. J. (1983). The experience of being different. In D. R. Copeland, B. Pfefferbaum, & A. J. Stovall (Eds.), The mind of the child who is said to be sick (pp. 13–14). Springfield, IL: Charles C. Thomas.
- Deasy–Spinetta, P. (1981). The school and the child with cancer. In J. J. Spinetta, & P. Deasy–Spinetta (Eds.), Living with childhood cancer (pp. 153–168). St. Louis: Mosby.
- Ekert, H. (1983). Long term needs of children and parents with chronic life threatening diseases. Australian Family Physician, 12, 237–241.
- Fagerhaugh, S. Y. (1986). Analyzing data for basic social processes. In W. C. C. & J. M. Swanson (Ed.), From practice to grounded theory: Qualitative research in nursing (pp. 133–145). Menlo Park, CA: Addison–Wesley.
- Fife, B., Norton, J., & Groom, G. (1987). The family's adaptation to childhood leukemia. Social Science in Medicine, 24, 159–168.

- Fisher, L. F. (1982). Transactional theories but individual assessment: A frequent discrepancy in family research. Family Process, 21, 313–320.
- Freund, B. L., & Siegel, K. (1986). Problems in transition following bone marrow transplantation: Psychosocial aspects. American Journal of Orthopsychiatry, 56, 244–252.
- Friedman, S., Chodhoff, P., Mason, J., & Hamburg, D. (1963). Behavioral observations of parents anticipating the death of a child. Pediatrics, 32, 610–625.
- Friedman, S. B. (1967). Care of the family of the child with cancer. Pediatrics, 40(Supp), 498–504.
- Futterman, E. H., & Hoffman, E. I. (1973). Crisis and adaptation in the families of fatally ill children. In E. J. Anthony, & C. Koupornik (Ed.), The child and his family: The impact of disease and death (pp. 127–143). New York: John Wiley.
- Geist, R. A. (1979). Onset of chronic illness in children and adolescents: Psychotherapeutic and consultative intervention. American Journal of Orthopsychiatry, 49, 4–23.
- George, L. K. (1982). Models of transitions in middle and later life. The Annals of the American Academy of Political and Social Sciences, 464, 22–37.
- Gillis, C. L. (1983). The family as a unit of analysis: Strategies for the nurse researcher. Advances in Nursing Science, 5(3), 50–59.
- Glaser, B. G. (1978). Theoretical Sensitivity. Mill Valley, CA: Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. New York: Aldine de Gruyter.
- Glaser, B. G., & Strauss, A. L. (1971). Status passage. Chicago: Aldine.
- Gogan, J. L., O'Malley, J. E., & Foster, D. J. (1977). Treating the pediatric cancer patient: A review. Journal of Pediatric Psychology, 2(2), 42–48.
- Golan, J. (1981). Passing through transitions: A guide for practitioners. New York: The Free Press.
- Green, M., & Solnit, A. J. (1964). Reactions to the threatened loss of a child: A vulnerable child syndrome. Pediatrics, 34, 58–66.



- Greenberg, H. S., Kazak, A. E., & Meadows, A. T. (1989). Psychologic functioning in 8- to 16-year-old cancer survivors and their parents. The Journal of Pediatrics, 114, 488-493.
- Hanigan, M. J. (1988). Healthy sibling's perception of living with a brother or sister who has leukemia (Abstract). Oncology Nursing Forum, 15(Supp), 135.
- Hoffman, I., & Futterman, E. H. (1971). Coping with waiting: Psychiatric intervention and study in the waiting room of a pediatric oncology clinic. Comprehensive Psychiatry, 12, 67-81.
- Hopson, B. (1977). Response to the papers by Schlossberg, Brammer and Abrego. The Counseling Psychologist, 9(2), 36-39.
- Hultsch, D. F., & Plemons, J. K. (1979). Life events and life-span development. In P. B. Baltes, & O. G. Brim (Eds.), Life span development and behavior (pp. 1-31). New York: Academic Press.
- Hutchinson, S. (1986). Grounded theory: The method. In P. L. Munhall, & C. J. Oiler (Eds.), Nursing research: A qualitative perspective (pp. 111-130). Norwalk, CT: Appleton-Century-Crofts.
- Iles, J. P. (1979). Children with cancer: Healthy siblings' perceptions during the illness experience. Cancer Nursing, 2, 371-377.
- Jaffe, N. (1984). Late sequelae of cancer therapy. In W. W. Sutow, D. J. Fernbach, & T. J. Vietti (Eds.), Clinical pediatric oncology (pp. 810-832). St. Louis: Mosby.
- Jenkin, R. D. T., Anderson, J. R., Chilcote, R. R., Coccia, P. F., Exelby, P. R., Kersey, J. H., Kushner, J. H., Meadows, A. T., Siegel, S. E., Sposto, R., Wilson, J. F., & Hammond, G. D. (1984). The treatment of localized non-Hodgkin's lymphoma in children: A report from the Children's Cancer Study Group. Journal of Clinical Oncology, 2, 88-97.
- Johnson, F. L., Rudolph, L., & Hartman, J. (1979). Helping the family cope with childhood cancer. Psychosomatics, 20, 241-251.
- Kadota, R. P., & Smithson, W. A. (1984). Bone marrow transplantation for diseases of childhood. Mayo Clinic Proceedings, 59, 171-184.
- Kagen-Goodheart, L. (1977). Reentry: Living with childhood cancer. American Journal of Orthopsychiatry, 47, 651-658.
- Kaplan, D. M., Grobstein, R., & Smith, A. (1976). Predicting the impact of severe illness in families. Health and Social Work, 1, 72-82.

- Karon, M. K., & Vernick, J. (1968). An approach to the emotional support of fatally ill children. Clinical Pediatrics, 7, 274–280.
- Kellerman, J., Rigler, D., & Siegel, S. E. (1977). The psychological effects of isolation in protected environments. American Journal of Psychiatry, 134, 563–565.
- Kellerman, J., Zeltzer, L., Ellenberg, L., Dash, J., & Rigler, D. (1980). Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control. The Journal of Pediatrics, 97, 126.
- Kirk, J., & Miller, M. L. (1986). Reliability and validity in qualitative research. Beverly Hills, CA: Sage.
- Knapp, R. J. (1986). Beyond endurance: When a child dies. New York: Schocken Books.
- Koch, A. (1985). "If only it could be me": The families of pediatric cancer patients. Family Relations, 34, 63–70.
- Koch-Hattem, A. (1986). Siblings' experience of pediatric cancer: Interviews with children. Health and Social Work, 11, 107–117.
- Koocher, G. P., & O'Malley, J. E. (1981). The damocles syndrome. New York: McGraw-Hill.
- Koocher, G. P., O'Malley, J. E., & Foster, D. J. (1981). The special problems of survivors. In G. P. Koocher, & J. E. O'Malley (Eds.), The damocles syndrome (pp. 112–129). New York: McGraw-Hill.
- Koocher, G. P., O'Malley, J. E., Gogan, J. L., & Foster, D. J. (1980). Psychological adjustment among pediatric cancer survivors. Journal of Child Psychology and Psychiatry, 21, 163–173.
- Kramer, R. F. (1984). Living with childhood cancer: Impact on the healthy siblings. Oncology Nursing Forum, 11(1), 44–51.
- Kramer, R. F., & Moore, I. M. (1983). Childhood cancer: meeting the special needs of healthy siblings. Cancer Nursing, 6, 213–217.
- Krell, R., & Rabkin, L. (1979). The effects of sibling death on the surviving child: A family perspective. Family Process, 18, 471–477.
- Kupst, M. J., & Schulman, J. L. (1980). Family coping with leukemia in a child: Initial reactions. In J. L. Schulman, & M. J. Kupst (Eds.), The child with cancer (pp. 111–128). Springfield, IL: Charles C. Thomas.

- Kupst, M. J., & Schulman, J. L. (1988). Long-term coping with pediatric leukemia: A six-year follow-up study. Journal of Pediatric Psychology, 13(1), 7-22.
- Kupst, M. J., Schulman, J. L., Maurer, H., Morgan, E., Honig, G., & Fochtman, D. (1984). Coping with pediatric leukemia: A two-year follow-up. Journal of Pediatric Psychology, 9, 149-163.
- Lansky, S. B. (1974). Childhood leukemia: The child psychiatrist as a member of the oncology team. Journal of the American Academy of Child Psychiatry, 13, 499-508.
- Lansky, S. B., Cairns, N. U., Hassanein, R., Wehr, J., & Lowman, J. T. (1978). Childhood cancer: Parental discord and divorce. Pediatrics, 62, 184-188.
- Lascari, A. D., & Stehens, J. A. (1973). The reactions of families to childhood leukemia. Clinical Pediatrics, 12, 210-214.
- Lavigne, J. V., & Ryan, M. (1979). Psychologic adjustment of siblings of children with chronic illness. Pediatrics, 63, 616-627.
- Lazarus, R. S. (1981, July). Little hassles can be hazardous to health. Psychology Today, 58-62.
- Levinson, D. J., Darrow, C. N., Klein, E. B., Levinson, M. H., & McKee, B. (1978). The seasons of a man's life. New York: Ballantine Books.
- Lopez-Ibor, B., & Schwartz, A. D. (1985). Neuroblastoma. Pediatric Clinics of North America, 32, 755-778.
- Lowenthal, M. F., Thurnher, M., & Chiriboga, D. (1975). Preface. In M. F. Lowenthal, M. Thurnher, & D. Chiriboga (Ed.), Four stages of life (pp. ix-xviii). San Francisco: Jossey-Bass.
- Magni, G., Carli, M., De Leo, D., Tshilolo, M., & Zanesco, L. (1986). Longitudinal evaluations of psychological distress in parents of children with malignancies. Acta Paediatrica Scandinavica, 75, 283-288.
- Magni, G., Messina, C., De Leo, D., Mosconi, A., & Carli, M. (1983). Psychological distress in parents of children with acute lymphatic leukemia. Acta Psychiatrica Scandinavica, 68, 297-300.
- Magni, G., Silvestro, A., Carli, M., & De Leo, D. (1986). Social support and psychological distress of parents of children with acute lymphocytic leukaemia. British Journal of Medical Psychology, 59, 383-385.

- Magni, G., Silvestro, A., Tamiello, M., Zanesco, L., & Carli, M. (1988). An integrated approach to the assessment of family adjustment to acute lymphocytic leukemia. Acta Psychiatrica Scandinavica, 78, 639–642.
- Maguire, G. P. (1983). The psychological sequelae of childhood leukemia. Recent Results in Cancer Research, 88, 47–56.
- Mauer, A. M. (1987). The concept of cure in pediatric oncology: Altered realities. The American Journal of Pediatric Hematology/Oncology, 9, 58–61.
- Messick, S. (1980). Test validity and the ethics of assessment. American Psychologist, 35, 1012–1027.
- Mishel, M. H. (1984). Perceived uncertainty and stress in illness. Research in Nursing and Health, 7, 163–171.
- Mishel, M. H. (1988). Uncertainty in Illness. Image, 20, 225–232.
- Morrow, G. R., Carpenter, P. J., & Hoagland, A. C. (1984). The role of social support in parental adjustment to pediatric cancer. Journal of Pediatric Psychology, 9, 317–329.
- Murstein, B. I. (1960). The effect of long-term illness of children on the emotional adjustment of parents. Child Development, 31, 157–171.
- Natterson, J. M., & Knudson, A. G. (1960). Observations concerning the fear of death in fatally ill children and their mothers. Psychosomatic Medicine, 22, 456–465.
- Neglia, J. P., & Robison, L. L. (1988). Epidemiology of the childhood leukemias. Pediatric Clinics of North America, 35, 675–692.
- O'Brien, P. E. (1988). Parent's initial experience with childhood acute lymphocytic leukemia. Doctoral Dissertation, University of Michigan, Ann Arbor. (From Dissertation Abstracts International, 49(12), 3629A).
- Parkes, C. M. (1971). Psycho-social transitions: A field for study. Social Science and Medicine, 5, 101–115.
- Peck, B. (1979, May 19). Effects of childhood cancer on long-term survivors and their families. British Medical Journal, 1(6174), 1327–1329.
- Pinkel, D. (1987). Curing children of leukemia. Cancer, 59, 1683–1691.
- Podrasky, P. A. (1986). The family perspective of the cured patient. Cancer, 58, 522–523.

- Polkinghorne, D. (1983). Methodology for the human sciences: Systems of inquiry. Albany, NY: State University of New York Press.
- Powazek, M., Payne, J. S., Goff, J. R., Paulson, M. A., & Stagner, S. (1980). Psychosocial ramifications of childhood leukemia: One year post-diagnosis. In J. L. Schulman, & M. J. Kupst (Eds.), The child with cancer (pp. 143-155). Springfield, IL: Charles C. Thomas.
- Quinn, J. J. (1985). Bone marrow transplantation in the management of childhood cancer. Pediatric Clinics of North America, 32, 811-833.
- Quint, J. C. (1969). Becoming diabetic: A study of emerging identity. Unpublished doctoral dissertation, University of California-San Francisco, San Francisco.
- Rapoport, R. (1963). Normal crises, family structure and mental health. Family Process, 2, 68-80.
- Sawyer, M., Crettenden, A., & Toogood, I. (1986). Psychological Adjustment of families of children and adolescents treated from leukemia. The American Journal of Pediatric Hematology/Oncology, 8, 200-207.
- Schlossberg, N. K. (1984). Counseling adults in transition. New York: Springer.
- Silverberg, E., & Lubera, J. A. (1988). Cancer statistics, 1988. Ca-A Cancer Journal for Clinicians, 8, 5-22.
- Silverman, P. R. (1982). Transitions and models of intervention. Annals of the American Academy of Political and Social Sciences, 464, 174-187.
- Smith, K. E., Ackerson, J. D., & Blotcky, A. D. (1989). Reducing distress during invasive medical procedures: Relating behavioral interventions to preferred coping style in pediatric cancer patients. Journal of Pediatric Psychology, 14, 405-419.
- Soccorsi, S., Rubbini Paglia, P., Lombardi, F., Riccardi, R., & Mastrangelo, R. (1988, March). Children with cancer: Influence of cancer treatment on the family structure (Abstract). Annual Meeting of the American Society of Clinical Oncologists, 7, 271.
- Sourkes, B. M. (1980). Siblings of the pediatric cancer patient. In J. Kellerman (Ed.), Psychological aspects of childhood cancer (pp. 47-69). Springfield, IL: Charles C. Thomas.
- Spinetta, J. J. (1977). Adjustment in children with cancer. Journal of Pediatric Psychology, 2(2), 49-51.

- Spinetta, J. J. (1978). Communication patterns in families dealing with life-threatening illness. In O. J. Z. Sahler (Ed.), The child and death (pp. 43–51). St. Louis: Mosby.
- Spinetta, J. J. (1981). The sibling of the child with cancer. In J. J. Spinetta, & P. Deasy-Spinetta (Eds.), Living with childhood cancer (pp. 133–142). St. Louis: Mosby.
- Spinetta, J. J. (1984). Measurement of family function, communication and cultural effects. Cancer, 53, 2330–2338.
- Spinetta, J. J., & Deasy-Spinetta, P. (1981). Talking with children who have a life threatening illness. In J. J. Spinetta, & P. Deasy-Spinetta (Eds.), Living with childhood cancer (pp. 234–251). St. Louis: Mosby.
- Spinetta, J. J., Deasy-Spinetta, P., McLaren, H. H., Kung, F. J., Schwartz, D. B., & Hartman, G. A. (1982). The adolescent's psychosocial response to cancer. In C. K. Tebbi (Ed.), Pediatric and adolescent oncology (pp. 312–346). Boston: G. K. Hall Medical.
- Spinetta, J. J., & Maloney, L. J. (1975). Death anxiety in the outpatient leukemic child. Pediatrics, 53, 1034–1037.
- Spinetta, J. J., Rigler, D., & Karon, M. (1973). Anxiety in the dying child. Pediatrics, 52(6), 841–845.
- Spinetta, J. J., Rigler, D., & Karon, M. (1974). Personal space as a measure of a dying child's sense of isolation. Journal of Consulting and Clinical Psychology, 42, 751–756.
- Spinetta, J. J., Swarner, J. A., & Sheposh, J. P. (1981). Effective parental coping following the death of a child from cancer. Journal of Pediatric Psychology, 6, 251–262.
- Stehbens, J. A., & Lascari, A. D. (1974). Psychological follow-up of families with childhood cancer. Journal of Clinical Psychology, 30, 394–397.
- Strauss, A. L. (1988). Qualitative analysis for social scientists. Cambridge: Cambridge University Press.
- Strauss, A. L., Corbin, J., Fagerhaugh, S., Glaser, B. G., Maines, D., Suczek, B., & Weiner, C. L. (1984). Chronic illness and the quality of life. St. Louis: Mosby.
- Strong, L. C. (1984). Genetics, etiology, and epidemiology of childhood cancer. In W. W. Sutow, D. J. Fernbach, & T. J. Vietti (Eds.), Clinical pediatric oncology (pp. 14–41). St. Louis: Mosby.

- Sutow, W. W. (1984). General aspects of childhood cancer. In W. W. Sutow, D. J. Fernbach, & T. J. Vietti (Eds.), Clinical Pediatric Oncology (pp. 1–13). St. Louis: Mosby.
- Sutow, W. W., Fernbach, D. J., & Vietti, T. J. (Eds.). (1984). Clinical pediatric oncology. St. Louis: Mosby.
- Swenson, B. J., & Stewart, B. J. (1987). Patterns of impairment: Childhood cancer. In M. H. Rose, & R. B. Thomas (Eds.), Children with chronic conditions (pp. 178–212). Orlando, FL: Grune & Stratton.
- Tapley, N. D., Strong, L. C., & Sutow, W. W. (1984). Retinoblastoma. In W. W. Sutow & T. J. Vietti (Eds.), Clinical pediatric oncology (pp. 539–558). St. Louis: Mosby.
- Tietz, W., McSherry, L., & Britt, B. (1977). Family sequelae after a child's death due to cancer. American Journal of Psychotherapy, *31*, 417–425.
- Tiller, J. W. G., Ekert, H., & Rickards, W. S. (1977). Family reactions in childhood acute lymphoblastic leukemia in remission. Australian Paediatric Journal, *13*, 176–181.
- Tornberg, M., McGrath, B., & Benoliel, J. (1984). Oncology transition services. Cancer Nursing, *7*(2), 31–137.
- van de Vliert, E., & Allen, B. L. (1984). Managing transitional strain: Strategies and intervention techniques. In V. L. Allen, & E. v. d. Vliert (Ed.), Role transitions: Explorations and explanations (pp. 345–355). New York: Plenum Press.
- Van Dongen–Melman, J. E. W. M., & Sanders–Woudstra, J. A. R. (1986). Psychosocial aspects of childhood cancer: A review of the literature. Journal of Child Psychology and Psychiatry, *27*, 145–180.
- Walker, C. L. (1988). Stress and coping in siblings of childhood cancer patients. Nursing Research, *37*, 208–212.
- Wapner, S. (1981). Transactions of persons–in–environments: Some critical transitions. Journal of Environmental Psychology, *1*, 223–239.
- Wapner, S., Kaplan, B., & Ciottone, R. (1981). Self–world relationships in critical environmental transitions: Childhood and beyond. In L. S. Liben, A. H. Patterson, & N. Newcombe (Eds.), Spatial representation and behavior across the life span (pp. 251–282). New York: Academic Press.

- Wasserman, A. L., Thompson, E. I., Wilimas, J. A., & Fairclough, D. L. (1987). The psychological status of survivors of childhood/adolescent Hodgkin's disease. American Journal of Diseases of Children, 141, 626-631.
- Watzlawick, P., Beavin, J. H., & Jackson, D. D. (1967). Pragmatics of human communication. New York: Norton.
- Weiss, R. S. (1976). Transition states and other stressful situations: Their nature and programs for their management. In G. Caplan, & M. Killilea (Eds.), Support systems and mutual help: Multidisciplinary explorations (pp. 213-232). New York: Grune & Stratton.
- Wells, L., Heiney, S. P., Cannon, B., Ettinger, R., & Ettinger, S. (1987). The effects of group therapy on parents of children with cancer. Journal of the Association of Pediatric Oncology Nurses, 4(1-2), 41.
- Wells, L. M., Heiney, S. P., Swygert, E., Troficanto, G., & Stokes, C. (1989). Psychosocial stressors, coping resources, and information needs of parents of adolescent cancer patients. Journal of the Association of Pediatric Oncology Nurses, 6(2), 23-24.
- Wilson, J. F., Jenkin, R. D. T., Anderson, J. R., Chilcote, R. R., Coccia, P., Exelby, P. R., Kersey, J., Kjeldsberg, C. R., Kushner, J., Meadows, A., Sheehan, W. W., Siegel, S., Sposto, R., Leikin, S., & Hammond, D. (1984). Studies on the pathology of non-Hodgkin's lymphoma of childhood. Cancer, 53, 1695-1704.
- Young, J. L., Ries, L. G., Silverberg, E., Horm, J. W., & Miller, R. W. (1986). Cancer incidence, survival, and mortality for children younger than age 15 years. Cancer, 58, 598-602.
- Zeltzer, L., Kellerman, J., Ellenberg, L., Dash, J., & Rigler, D. (1980). Psychologic effects of illness in adolescence, II. Impact of illness in adolescents—crucial issues and coping styles. The Journal of Pediatrics, 97, 132-138.



Appendix A  
Interview Schedules

## **Interview Schedules**

### Interview 1 Questions

1. Tell me who is in your family.
  - a. Your immediate family. Your extended family.
  - b. Are there any other person's who are important in your family life right now?
2. Could you tell me about when your child first got sick?
3. What has it been like since your child first got sick? What is it like right now? How is that different from before your child got sick?
4. How have things changed in the daily life of your family since your child's illness?
  - a. How has the illness limited your family?
  - b. How has the illness made positive contributions to your family life?
  - c. How has the illness affected your relationships with your children?
  - d. How has the illness affected your relationship with your husband/wife?
5. How has your own life changed since your child's illness?
6. How do you feel about your child's illness?

### Interview 2

1. Can you tell me about when your child went into remission?
2. What has it been like since your child went into remission?
3. How have things changed in the daily life of your family since your child went into remission?
4. How has your own life changed since your child went into remission?

Interview 2 (continued)

5. How do you feel now that your child is in remission?
6. What does remission mean to you?

Combined Interviews 1 and 2 for Families whose Child has Instantaneous Remission

1. Tell me who is in your family.
  - a. Your immediate family. Your extended family.
  - b. Are there any person's important in your family life right now?
2. Could you tell me about when your child first got sick?
3. What has it been like since your child first got sick? What is it like right now? How is that different from before your child got sick?
4. What does the fact that your child is in remission mean to you?
5. How have things changed in the daily life of your family since your child's illness?
  - a. How has the illness limited your family?
  - b. How has the illness made positive contributions to your family life?
  - c. How has the illness affected your relationships with your children?
  - d. How has the illness affected your relationship with your husband/wife?
6. How has your own life changed since your child's illness?
7. How do you feel about your child's illness?

## **Interview Schedules for Children**

### Interview 1 Questions

1. Tell me who is in your family.
  - a. Who lives with you?
  - b. Is there anyone else who is important to your family right now?
2. Could you tell me about when your brother/sister/you first got sick?
3. What has it been like since your brother/sister/you first got sick? What is it like right now? How is that different from before your brother/sister/you got sick?
4. How have things changed in your family since your brother/ sister/you got sick?
  - a. Have there been any good changes?
  - b. Have there been any changes which are not so good?
  - c. How are things with your mother?
  - d. How are things with your father?
  - e. How are things with your brother/sister?
5. How has your life changed since your brother/sister/you got sick?
6. How do you feel about your brother/sister's/your sickness?

### Interview 2

1. Have you heard of the word "remission"? What does that word mean to you?  
Do you know that your brother/sister/you is/are in remission?
2. What does it mean to you that your brother/sister/you is/are in remission?
3. Can you tell me about when your brother/sister/you went into remission?
4. What has it been like since your brother/sister/you went into remission?

Interview 2 (continued)

5. How have things changed in your family since your brother/ sister/you went into remission?
  - a. How are things with your mother?
  - b. How are things with your father?
  - c. How are things with your brother/sister?
6. How has your own life changed since your brother/sister/you went into remission?
7. How do you feel now that your brother/sister/you is in remission?

Combined Interviews 1 and 2 for Children Who Achieved an Instantaneous Remission

1. Tell me who is in your family.
  - a. Who lives with you?
  - b. Is there any one else who is important to your family right now?
2. Could you tell me about when your brother/sister/you first got sick?
3. What has it been like since your brother/sister/you first got sick? What is it like right now? How is that different from before your brother/sister/you got sick?
4. Have you heard of the word remission? What does it mean that you/your brother/sister are/is in remission?
5. How have things changed in your family since your brother/ sister/you got sick?
  - a. Have there been any good changes?

Interview 2 (continued)

- b. Have there been any changes which are not so good?
  - c. How are things with your mother?
  - d. How are things with your father?
  - e. How are things with your brother/sister?
6. How has your life changed since your brother/sister/you got sick?
7. How do you feel about your brother/sister's/your sickness?

Family Interview 3

1. Can you tell me how \_\_\_'s diagnosis affected your family?
  - a. Who handles clinic appointments/hospitalizations?
  - b. Who takes care of things at home during those times?
  - c. Is that different from before?
  
2. How have things changed in the daily life of your family since the diagnosis?
  - a. Since \_\_\_ went into remission?
  - b. Have any of those changes been positive in any way?
  - c. How have any of those changes been negative?
  
3. What does it mean for your family that \_\_\_ has cancer?
  - a. That she/he is in remission?

Appendix B  
Family Information Sheet



FAMILY #: \_\_\_\_\_

**Family Information Sheet**

1. Please list the names and ages of all family members.

---



---



---



---



---



---



---



---

2. What is the male parent's ethnic background?

- Caucasian  
 Hispanic  
 Asian  
 Black  
 Native American  
 Other

3. What is the female parent's ethnic background?

- Caucasian  
 Hispanic  
 Asian  
 Black  
 Native American  
 Other

4. What is the female parent's occupation?

---

5. What is the male parent's occupation?

---

6. What is (are) the religious affiliations of your family members? Check all that apply.

Protestant

Catholic

Jewish

Mormon

Other \_\_\_\_\_

(Please Specify)

7. Which category best describes your family's combined yearly income from all sources?

Less than \$5,000

\$5,001-\$15,000

\$15,001-\$25,000

\$25,001-\$35,000

\$35,001-\$45,000

\$45,001-\$55,000

\$55,001-\$75,000

over \$75,000

8. Please write in the highest year of education, and the highest degree of the female partner.

---



---

9. Please write in the highest year of education, and the highest degree of the male partner.

---



---

(Please turn page over and complete the other side.)

10. What is your ill child's diagnosis?

---

11. Does anyone else in your family have a chronic illness?

yes

no

If yes, who? (Please answer for all members of your family who have a chronic illness.)

---

What is/are his/her diagnosis?

---

Appendix C  
Consent Forms

**OREGON HEALTH SCIENCES UNIVERSITY  
SCHOOL OF NURSING  
INFORMED CONSENT FORM**



**TITLE:**           **The Experience of Families When a Child is Diagnosed with Cancer**

**INVESTIGATOR:**   Laura Clarke, RN, MS, Doctoral Student,  
Oregon Health Sciences University, School of Nursing  
503-279-7796 (W) 503-761-6085 (H)

**PRINCIPAL OBJECTIVES:** The purpose of this study is to describe the experiences a family has when a child is diagnosed with cancer. The study will consider each individual's and the family unit's perception of the changes in life as a result of childhood cancer.

**CHILDREN'S NAMES:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PARENT'S NAMES:**

\_\_\_\_\_

\_\_\_\_\_

We understand that our child's illness from cancer affects the entire family. This study looks at how each member of the family and the family unit responds to our child having cancer. As a result, a description of the family experience of childhood cancer will be written so that nurses can better understand families going through this and better help them cope with the illness.

As participants in this study, we understand that our family members will talk with the investigator 3 times in our home or some other place of our choosing. In the first two interviews we and each of our children over the age of 5 will talk with the investigator about what they see is happening in the family. Each person will talk with the researcher for about 20-30 minutes. This will mean that for a four person family, it will take 2 hours for the interviews to be completed. In the last interview, our family all together will talk with the investigator. This interview will last about an hour. This interview schedule may be changed based upon the course of our child's illness, if necessary.

We have had the chance to look at the questions which we will be asked as well as the questions which our children will be asked. We know that we can ask that any question not be asked of any or all of our children. We also know that we will be asked to fill out a form about our family income, education, ethnic background, and religious affiliation at the first interview.

Each of our children will have the opportunity to decide if he or she wants to participate in the study. The rest of the family's participation will not be affected by the decision of one or more family members not to participate.

We recognize that our family may benefit from this study by having a chance to talk about issues

that concern us, and by becoming more aware of those issues. The research will help doctors and nurses learn about what it is like for a family to have a child with cancer. We understand that answering some of the questions in this study may bring forth uncomfortable feelings such as sadness, concern, etc.

This study is being conducted to fulfill the requirements for the Philosophy of Science degree in nursing at the Oregon Health Sciences University. The results of this study will become part of a doctoral dissertation, and will be on file in the Health Sciences Library at the Oregon Health Sciences University. The questionnaires, transcripts, and tape recordings will be kept by the investigator for 5 years and then destroyed.

We understand that no one in our family will be personally identified in the report of this study and no names will be on the forms or transcripts following the interview. Each form and transcript will be identified only by a code name. The consent forms will be kept separate from the forms and transcripts and kept in a secure locked place by the investigator. Only the investigator and dissertation committee members will have access to the data. Neither our names nor our identity will be used for publication or publicity purposes.

This study is supported by a National Research Service Fellowship awarded by the National Center for Nursing Research. It is not the policy of the Department of Health and Human Services or any agency funding the study in which we are participating to compensate or provide medical treatment for human subjects in the event research results in physical injury. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation will be available to you only if you establish that the injury occurred through the fault of the University, its officers, or employees. If you have further questions, please call Dr. Michael Baird at (503) 279-8014.

We have had an opportunity to ask questions and understand that Laura Clarke, RN, MS has offered to answer any questions we may have in the future about the research or participants' rights. We understand we may refuse to participate or withdraw from this study at any time without affecting our relationship with or treatment at the Oregon Health Sciences University.

We have read the foregoing and agree to participate in this study.

---

Parent/Date

---

Parent/Date

---

Witness/Date

cc: Family  
Investigator's Files

**OREGON HEALTH SCIENCES UNIVERSITY  
SCHOOL OF NURSING**

**INFORMED ASSENT FOR CHILD PARTICIPANTS**

**TITLE:** The Experience of Families When a Child is Diagnosed with Cancer

**INVESTIGATOR:** Laura Clarke, RN, MS, Doctoral Student, Oregon Health Sciences University, School of Nursing; 503-279-7796 (W), 503-761-6085 (H)

**PRINCIPAL OBJECTIVES:** The purpose of this study is to describe the experiences a family has when a child is diagnosed with cancer. The study will consider each individual's and the family unit's perception of the changes in life as a result of childhood cancer.

Name: \_\_\_\_\_

I know that I am sick. The nurses that care for me are trying to learn about what it is like for a family to have someone who is sick like me. The nurses want to know what it is like for me and for my family now that I am sick. A nurse will come to see me three times, either in the hospital or at home to ask me questions about my sickness.

I know that I do not have to join this study or answer any questions. If I decide later that I do not want to be in the study, I can stop. If I do join the study and answer the questions, my answers will be studied by a nurse at the Oregon Health Sciences University to try to help families whose child is sick. My name will not be told to other people who read about this study or to my doctors.

I have been told that some of the questions which I will be asked by the nurse may make me sad or concerned. They might also help me to know about my sickness better.

This study has been explained to me. I want to be a part of it.

\_\_\_\_\_  
Signature/Date

\_\_\_\_\_  
Parent/Guardian/Date

\_\_\_\_\_  
Investigator/Date

**OREGON HEALTH SCIENCES UNIVERSITY  
SCHOOL OF NURSING**

**STATEMENT TO GAIN VERBAL ASSENT FROM 5-6 YEARS**

**TITLE:** The Experience of Families When a Child is Diagnosed with Cancer

**INVESTIGATOR:** Laura Clarke, RN, MS, Doctoral Student, Oregon Health Sciences University, School of Nursing; 503-279-7796 (W), 503-761-6085 (H)

**PRINCIPAL OBJECTIVES:** The purpose of this study is to describe the experiences a family has when a child is diagnosed with cancer. The study will consider each individual's and the family unit's perception of the changes in life as a result of childhood cancer.

Name: \_\_\_\_\_

This study looks at what is like for families to have a child who is sick. We want to know what it has been like for your family since you got sick. I will visit you three times. Each time, I will be asking you some questions about how things are different in your family since you found out you are sick. You do not have to join this study. If you join and then want to stop, you can. If you do join the study and answer the questions, your answers will be looked at by a nurse at the Oregon Health Sciences University to help other families whose child is sick. Your name will not be told to other people who read about the study, or to your doctors. Some of the questions I will ask may make you sad or unhappy. They might also help you know more about your sickness. Now that I have told you about the study do you have any questions? Is there anything you do not understand?

Do you wish to be a part of this study?

\_\_\_\_\_  
Signature/Date

\_\_\_\_\_  
Parent/Guardian/Date

\_\_\_\_\_  
Investigator/Date

**OREGON HEALTH SCIENCES UNIVERSITY  
SCHOOL OF NURSING**

**INFORMED ASSENT FOR CHILD PARTICIPANTS**

**TITLE:** The Experience of Families When a Child is Diagnosed with Cancer

**INVESTIGATOR:** Laura Clarke, RN, MS, Doctoral Student, Oregon Health Sciences University, School of Nursing; 503-279-7796 (W), 503-761-6085 (H)

**PRINCIPAL OBJECTIVES:** The purpose of this study is to describe the experiences a family has when a child is diagnosed with cancer. The study will consider each individual's and the family unit's perception of the changes in life as a result of childhood cancer.

Name: \_\_\_\_\_

I know that my brother is sick. The nurses that care for my brother's sickness are trying to learn about what it is like for a family to have someone who is sick like my brother. The nurses want to know what it is like for me and for my family now that my brother is sick. A nurse will come to see me at home three times to ask me questions about my family and my brother's sickness.

I know that I do not have to join this study or answer any questions. If I decide later that I do not want to be in the study, I can stop. If I do join the study and answer the questions, my answers will be studied by a nurse at the Oregon Health Sciences University to try to help families whose child is sick. My name will not be told to other people who read about this study.

I have been told that some of the questions which I will be asked by the nurse may make me sad or concerned. They might also help me to know about my brother's sickness better.

This study has been explained to me. I want to be a part of it.

\_\_\_\_\_  
Signature/Date

\_\_\_\_\_  
Parent/Guardian/Date

\_\_\_\_\_  
Investigator/Date



**OREGON HEALTH SCIENCES UNIVERSITY  
SCHOOL OF NURSING**

**STATEMENT TO GAIN VERBAL ASSENT FROM 5-6 YEARS**

**TITLE:** The Experience of Families When a Child is Diagnosed with Cancer

**INVESTIGATOR:** Laura Clarke, RN, MS, Doctoral Student, Oregon Health Sciences University, School of Nursing; 503-279-7796 (W), 503-761-6085 (H)

**PRINCIPAL OBJECTIVES:** The purpose of this study is to describe the experiences a family has when a child is diagnosed with cancer. The study will consider each individual's and the family unit's perception of the changes in life as a result of childhood cancer.

Name: \_\_\_\_\_

This study looks at what is like for families to have a child who is sick. We want to know what it has been like for your family since your brother got sick. I will visit you three times. Each time, I will be asking you some questions about how things are different in your family since you found out your brother is sick. You do not have to join this study. If you join and then want to stop, you can. If you do join the study and answer the questions, your answers will be looked at by a nurse at the Oregon Health Sciences University to help other families whose child is sick. Your name will not be told to other people who read about the study. Some of the questions I will ask may make you sad or unhappy. They might also help you know more about your brother's sickness. Now that I have told you about the study do you have any questions? Is there anything you do not understand?

Do you wish to be a part of this study?

\_\_\_\_\_  
Signature/Date

\_\_\_\_\_  
Parent/Guardian/Date

\_\_\_\_\_  
Investigator/Date

**OREGON HEALTH SCIENCES UNIVERSITY  
SCHOOL OF NURSING**

**INFORMED ASSENT FOR CHILD PARTICIPANTS**

**TITLE:** The Experience of Families When a Child is Diagnosed with Cancer

**INVESTIGATOR:** Laura Clarke, RN, MS, Doctoral Student, Oregon Health Sciences University, School of Nursing; 503-279-7796 (W), 503-761-6085 (H)

**PRINCIPAL OBJECTIVES:** The purpose of this study is to describe the experiences a family has when a child is diagnosed with cancer. The study will consider each individual's and the family unit's perception of the changes in life as a result of childhood cancer.

Name: \_\_\_\_\_

I know that my sister is sick. The nurses that care for my sister's sickness are trying to learn about what it is like for a family to have someone who is sick like my sister. The nurses want to know what it is like for me and for my family now that my sister is sick. A nurse will come to see me at home three times to ask me questions about my family and my sister's sickness.

I know that I do not have to join this study or answer any questions. If I decide later that I do not want to be in the study, I can stop. If I do join the study and answer the questions, my answers will be studied by a nurse at the Oregon Health Sciences University to try to help families whose child is sick. My name will not be told to other people who read about this study.

I have been told that some of the questions which I will be asked by the nurse may make me sad or concerned. They might also help me to know about my sister's sickness better.

This study has been explained to me. I want to be a part of it.

\_\_\_\_\_  
Signature/Date

\_\_\_\_\_  
Parent/Guardian/Date

\_\_\_\_\_  
Investigator/Date

**OREGON HEALTH SCIENCES UNIVERSITY  
SCHOOL OF NURSING**

**STATEMENT TO GAIN VERBAL ASSENT FROM 5-6 YEARS**

**TITLE:** The Experience of Families When a Child is Diagnosed with Cancer

**INVESTIGATOR:** Laura Clarke, RN, MS, Doctoral Student, Oregon Health Sciences University, School of Nursing; 503-279-7796 (W), 503-761-6085 (H)

**PRINCIPAL OBJECTIVES:** The purpose of this study is to describe the experiences a family has when a child is diagnosed with cancer. The study will consider each individual's and the family unit's perception of the changes in life as a result of childhood cancer.

Name: \_\_\_\_\_

This study looks at what is like for families to have a child who is sick. We want to know what it has been like for your family since your sister got sick. I will visit you three times. Each time, I will be asking you some questions about how things are different in your family since you found out your sister is sick. You do not have to join this study. If you join and then want to stop, you can. If you do join the study and answer the questions, your answers will be looked at by a nurse at the Oregon Health Sciences University to help other families whose child is sick. Your name will not be told to other people who read about the study. Some of the questions I will ask may make you sad or unhappy. They might also help you know more about your sister's sickness. Now that I have told you about the study do you have any questions? Is there anything you do not understand?

Do you wish to be a part of this study?

\_\_\_\_\_  
Signature/Date

\_\_\_\_\_  
Parent/Guardian/Date

\_\_\_\_\_  
Investigator/Date

Appendix D  
Family Interview Code Sheet Example

# Coding Dictionary - Family 4 Interview 3 (1-11-90)

Code	Definition	Examples
Easier		<p>"Not quite as much. Before it took a lot more energy." F4P113</p> <p>"There's not so much." F4P113</p> <p>"Well it is a lot easier. The second month she had three spinal taps to go through. But now it's once, every 32 days she has a spinal tap. So that is a lot easier on her too." F4P213</p> <p>"...now that we are through the first month which was major stress everything is easing a little bit. It is going a little more smoothly." F4P113</p>
More Better Days		<p>"There's more better days...She has better days at times." F4P113</p>
Burden on Mom		<p>"Course it's more taxing on [my wife] than me cause she's the one that goes up for her overnights and her, oh, four hours, her maintenance and then go on working all the time. Most of it falls on [my wife].... There's days she's wore out when she gets back." F4P113</p>
Day Care for Sibbs		<p>"Just physically having to find the places for all the kids." F4P113</p> <p>"...getting babysitters for the next time...Hate to wear our welcome out at certain places and try and spread it out so it's no burden to anybody and but it is something that you've got to come up with three times a month and have to, you know, have to sit down and try to figure out who might be talked into it next time." F4P113</p>

# Coding Dictionary - Family 4 Interview 3 (p. 2)

<i>Code</i>	<i>Definition</i>	<i>Examples</i>
Unpredictability		<p>"If she can have all of her stuff done on one day. It, if she reacts poorly to one thing we would have to come back." F4P113</p> <p>"...medication...causes a complete change in her and every time that comes on we know what we are going to expect and kind of what we have to go through for the, well, the five days that she is on it." F4P113</p>
More Normal		<p>"I think it's given us, probably back to normal. Since we have been here more and it has not been near as much times as she has had to go up there as before." F4P213</p> <p>"But I keep up the day-to-day cleaning. It isn't as bad as it was." F4P213</p> <p>"It's not normal. I don't think it'll probably be normal until maybe two years after she is done. I just sort of set myself for that." F4P213</p> <p>"Yeah, it definitely is different than normal." F4P113</p> <p>"...it's definitely not our daughter but it is the thing that is going to be normal now for the next sixteen months...which will be a normal for us...That is, it isn't normal by all means." F4P113</p> <p>"And in those lines it's a normal but we have to always adjust once we know what the medicine is doing to her. You know, along the lines of emotionally, uh, physically and you just have to cope with that." F4P113</p> <p>"Sometimes I feel normal, I almost feel too comfortable and then I realize that I am feeling too comfortable and I catch myself...it is seeming more of the normal because she's doing OK." F4P213</p>

# Coding Dictionary - Family 4 Interview 3 (p. 3)

Code	Definition	Examples
<p>Unsettling</p> <p>Threat to Family Integrity</p> <ul style="list-style-type: none"> <li>◆ Extended Family Ties Split</li> </ul> <p>Meaning of Illness</p>		<p>"It's unsettling." F4P2J3</p> <p>"My Aunt and my grandma, they called Children's Services and said that my Mom is abusing me and [my sister], that she had to take us away, but she didn't." F4P3J3</p> <p>"They didn't agree with me in using, well, actually I put her in time out. They felt that I should not be disciplining her in any way. That I was being a little harsh, not abusive, but harsh. They felt that I should not be making her have normal limitations of the others due to the fact that she has cancer. So there was a great big fight over it and everything like that. But then Children's Services came to realize, you know, from the kids that it was unfounded. I think that's one thing they kept saying they couldn't see how they couldn't have handled it in the situations they were in. It came to be that they couldn't handle it and that's why they pushed themselves away from her...it was a total shock." F4P2J3</p> <p>"...they are not welcome in my home and they're off my Christmas list anyway." F4P1J3</p> <p>"I don't know. I wouldn't wish it on anybody. Bottom line." F4P1J3</p> <p>"The fear...That there's never really an end to it." F4P2J3</p> <p>"I hate it...the back pokes." F4P3J3</p> <p>"If she needed a bone marrow transplant, what would happen then?" F4P2J3</p>

## Coding Dictionary - Family 4 Interview 3 (p. 4)

Code	Definition	Examples
Discipline		<p>"...we have had to get back in more, is getting back into discipline." F4P2J3</p>
Financial Concerns		<p>"They had a little fund raiser for her, a car show." F4P2J3</p> <p>"That's helped quite a bit and she is now under SSI and they have cleared that so that has taken a large burden off that." F4P1J3</p>
Response to Illness ◆ Realize Mortality		<p>"It [my guard] is up with the other children as well...not just symptoms, but the accidents, and you realize the mortality of everybody." F4P2J3</p>
Tension between Mom's Pessimism and Dad's Optimism		<p>"Anything else positive, I can't see it." F4P2J3</p> <p>"...now that we are through the first month which was major stress everything is easing a little bit. It is going a little more smoothly. There's got to be some kind of a positive that keeps going, a positive like that." F4P1J3</p> <p>"Negative, no, not right at this point." F4P1J2</p> <p>"I know one of the negative changes, you know, is that her fear of bed. And fear of being away from home overnight." F4P2J3</p>
Personality Change		<p>"...medication causes a complete change in her...and it's definitely not our daughter." F4P1J3</p>



Appendix E  
Family Transition Summary Sheet

Family# 1  
 Date: 1-30-90

# Family Transition Summary Sheet

Interview 1	Interview 2	Interview 3
<p><b>Dominant Themes</b></p> <ul style="list-style-type: none"> <li>Evaluation/Shifting of Priorities</li> <li>Change/Adjustment Process</li> <li>Positive</li> <li>Sibling Response</li> <li>Managing Flow of Info</li> <li>Medical Management               <ul style="list-style-type: none"> <li>◆ Fear of Chemo</li> </ul> </li> <li>Preoccupation</li> </ul> <p>Expected Return to Normal</p> <p>Vulnerability</p> <p>Response to Diagnosis</p> <ul style="list-style-type: none"> <li>◆ Shock</li> <li>◆ Weird</li> </ul> <p>Sibling Rivalry</p> <p>Prediagnostic Period</p> <ul style="list-style-type: none"> <li>◆ Waiting</li> <li>◆ Not Knowing</li> </ul> <p>Religion as support</p> <p><b>Summary Statement:</b>          Has a moderated amount of coping resources, material, cognitive and emotional. Have a realistic perception of the illness, prognosis. Minimal effect on daily lives, yet a profound effect emotionally and emotionally. Major coping efforts are affective/cognitive. Family pulled together. Sibs are informed, yet not heavily involved.</p>	<p><b>Dominant Themes</b></p> <p>Not Applicable-Interview combined with interview 1</p> <p><b>Summary Statement:</b></p>	<p><b>Dominant Themes</b></p> <ul style="list-style-type: none"> <li>Change in Priorities</li> <li>Ill Child Coping</li> <li>Medical Management</li> <li>Appearance of Normal/ New Normal</li> <li>No Fear</li> <li>Sibling Response               <ul style="list-style-type: none"> <li>◆ Minimal Change for the Children</li> </ul> </li> <li>Added Stress &amp; Tension</li> <li>Sibling Response</li> <li>Normal Daily Routine</li> <li>Vulnerability</li> <li>Sibling Rivalry</li> <li>Wondering if Doctors are Withholding Information</li> <li>Religion as support</li> </ul> <p><b>Summary Statement:</b></p>
<p><b>Pervasive Themes:</b></p>	<p><b>Summary of Changes Over Time:</b></p>	

## Abstract

Title: The experience of families when a child is diagnosed with cancer with a favorable prognosis

Author: Laura Clarke–Steffen

Approved: \_\_\_\_\_  
Advisor

The major objective of this longitudinal, descriptive study was to describe the family transition to living with childhood cancer, from the family's point of view, when a child is diagnosed with cancer with a favorable prognosis. The major research question was: What is the experience of families when a child is diagnosed with cancer with a favorable prognosis?

A convenience sample consisted of 40 members of 7 families with a child recently diagnosed with cancer with a favorable prognosis at a northwestern health sciences university hospital. Cancer with a favorable prognosis was defined to be any subtype of cancer with greater than 60% long-term survival rate. At least one child in the family was 5 years old or older. All family members over 5 years of age participated.

The study used a grounded theory approach. Data collection consisted of three tape-recorded, semi-structured interviews with family members in the home. During the first two interviews, all family members over the age of five were interviewed individually. During the first interview, parent(s) completed a demographic questionnaire. The third interview was with the entire family together.

Interviews occurred at the time of diagnosis, at the time the child went into remission, and three months post remission. A modified grounded theory analysis was used.

The major finding was a model of the family transition in response to the diagnosis of childhood cancer. This transition was characterized by a fracturing of reality at the realization of the malignant nature of the illness, a period of limbo following the diagnosis, the utilization of strategies to reconstruct reality, and a "new normal" for the family. The transition process continued for the 4–5 month course of the study and, in all families, extended beyond the study period.

Factors limiting generalizability of the findings include the small sample size, single site, and the shortness of time families were followed. Implications for nursing practice include the family's need for continued nursing involvement throughout the illness trajectory, past medically defined remission and a need for nursing care to be family focused. Research implications include further exploration of the transition over a longer period of time, with a variety of illness trajectories and a larger sample.