

MOTHERS' ADAPTATION TO CHILDHOOD CANCER

An analysis of family process stressors,  
family system resources, parental coping patterns,  
and parental adaptation among mothers  
of children with cancer

by

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Dissertation submitted to the Faculty of the  
Virginia Polytechnic Institute and State University  
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Family and Child Development

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November, 1989

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(ABSTRACT)

Family process stressors, family system resources, parental coping patterns, and parental adaptation were assessed for 58 mothers who had a child with cancer who was being seen at selected pediatric hematology-oncology centers in two Southeastern states. The respondents completed a self-report questionnaire containing the Coping and Health Inventory for Parents, five subscales from the Family Environment Scale, and items asking demographic questions. The dependent measure was the Parental Adaptation Assessment, a modified version of the Spinetta Family Adjustment Scale, developed for this study to measure parents' perception of their adaptation to the experience of caring for a child with cancer. The criteria for subject inclusion in the study were: (a) two parents living in the home; and, (b) the child's cancer diagnosis was to have occurred not less than 3 months and not more than 4 years prior to data collection. The Double ABCX Model of Family Adaptation was used as the basis for variable selection.

Frequency distributions, correlations between the 11 independent variables and mother's adaptation, and a stepwise regression analysis were used to analyze the data. Two family process stressors (conflict and control) and two family system resources (cohesion and expressiveness) were significantly ( $p \leq .05$ ) correlated with mother's adaptation. The regression analyses showed that two variables (cohesion and mother's age) explained 34% of the variance in mother's adaptation.

Results show family cohesion and mother's age to be the only significant predictors of her perceived adaptation. Family process stressors and parental coping patterns failed to account for any significant variance in mother's adaptation. Implications for family stress theory, psychosocial oncology research, and family therapy practice are discussed. Recommendations for further research are suggested.

DEDICATED TO

my parents

who nurtured my love for learning  
and taught me to care about families in need

my daughter

who helped me to remember that "dada"  
is more important than data  
And most of all to my wife

who showed me that it could be done  
and nourished me with encouragement, support,  
love, patience, and humor  
every step of the way.

## ACKNOWLEDGEMENTS

First, I wish to acknowledge and express sincere appreciation to the parents who participated in the study.

Second, I want to express my thanks to the department heads and research coordinators at the data collection sites:

and ,  
Bowman Gray School of Medicine, Wake Forest University;

,  
Children's Hospital of The King's Daughters;

and ,  
Children's Medical Center of the University of Virginia;

and ,  
Duke University Medical Center;

and ,  
Medical College of Virginia.

And finally, I want to express my gratitude to the members of my advisory committee:

Dr. Rosemary Blieszner, Dr. Lawrence Cross, Dr. James Keller,  
Dr. Howard Protinsky, and Dr. Michael Sporakowski.

Special thanks to Dr. James Keller, Dr. Anne Herndon,  
Dr. Michael Sporakowski, Dr. Lawrence Cross,  
Dr. Thomas Meyers, and Dr. Alice Sewell  
who have provided valuable support at crucial times.

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## CHAPTER 1

### INTRODUCTION

This chapter explains why the study was done. It begins with an introduction to childhood cancer, emphasizing the stresses, resources, and coping responses involved in parental adaptation to the disease. The specific problem to be addressed by this study is then described. Finally, the significance of this study to family stress theory, psychosocial oncology, and family therapy will be discussed.

#### Childhood Cancer

Cancer is the leading cause of death by disease among children ages 3 to 14 (Waskerwitz & Ruccione, 1985). In 1989, an estimated 1,800 children in the United States died from the disease, about half of them from leukemia (American Cancer Society, 1989). This figure does not convey, however, the number of people such as parents, siblings, extended family members, and friends whose lives are also affected by the illness.

Although childhood cancer is life-threatening, it is no longer considered a swift and certain killer. In fact, the outlook for the survival of children with cancer has improved dramatically in recent years. Today,

treatment techniques capable of producing disease-free states (remissions) have increased the length of survival and, in some cases, brought about apparent cures. For example, in major cancer centers, 50% to 75% of children are being saved from acute leukemia, 90% of those with Wilms' tumor (a cancer of the kidney), 75% of those with Hodgkin's disease, and 70% to 80% of those with bone cancer. Overall, 39% of all children diagnosed with cancer are living 5 years after the initial diagnosis (American Cancer Society, 1989).

Because more children are now surviving cancer or living with the disease as a chronic illness, the long- and short-term effects of living with childhood cancer and cancer's impact upon the family have become important (Goodheart, 1977; Waskerwitz & Ruccione, 1985). One area of particular interest has been the parental response to childhood cancer (Chesler & Barbarin, 1987; McCubbin, 1988). Research indicates that parents repeatedly have been identified as the primary source of psychosocial support to the child with cancer, and that they bear the greatest responsibility for providing physical care for the child in the home (Northouse, 1984). In addition, parents of children with cancer are called upon to provide for the physical and emotional needs of all family members. How these parents cope with the

special needs and challenges of extended care for their child with cancer is the question underlying this study.

### The Family Disease Concept

Much of the literature on chronic illness supports the assumption that childhood cancer is a "family disease" (Northouse, 1984). This concept, based on family systems theory, suggests that illness in one family member sends reverberations throughout the entire family system (Bowen, 1976; Minnuchin, 1974). The reactions of the child with cancer affect family members, and family members' reactions affect the patient.

In writing about the family disease concept in pediatric cancer families, Holland (1982) has referred to the systemic condition as "psychosocial oncology" recognizing that "family members are under enormous stress -- as great as that of the cancer patient himself" (p. 19). However, within this systems framework, questions remain regarding the relationship between this intra-family stress, the family's resources and coping patterns, and adaptation among parents who have a child with cancer. These variables will be used to organize the following discussion of parental response to childhood cancer.

### Family Stress

Although childhood cancer, in general, can be viewed as a chronic, treatable illness, it is still life-threatening and stressful. Treatment efforts are not always successful, and children with cancer and their families may live with uncertainty and the fear of death. As a result, childhood cancer generates considerable stress and anxiety within a family system and often alters communication patterns, roles, and relationships among family members (Bowen, 1976; Cassileth & Hamilton, 1979; Koch, 1985).

Research which has focused on the impact of childhood cancer on parents has documented numerous stresses. According to a psychosocial model proposed by Van Dongen-Melman and associates (1986), these stresses typically involve parental uncertainty, loss of control, threats to self-esteem, and negative feelings. Chesler and Barbarin (1987) have organized the special stresses faced by parents of children with cancer under three key coping tasks. These family stress categories include: (1) management of internal emotional relationships, such as parental pain and exhaustion, sibling jealousy and concern; (2) adaptation to practical tasks, such as overload of new tasks, care for the ill child; and, (3) management of external relationships, such as financial

demands, reactions of extended family and friends. Although these and other models have generated useful ways of conceptualizing parental stress, few have been tested by examining the relationships between types of family stress, such as conflict and control, and subsequent parental adaptation.

### Parental Coping Patterns

Recent research on parental coping has begun to challenge the conventional wisdom that many families break apart as a result of the extended stress of childhood cancer (Lansky, Cairns, Hassamien, Wehr, & Lowman, 1978; McCubbin, Cauble, & Patterson, 1982). In some families, parents reported that they made positive changes in their prior patterns of relating to their spouses while adapting to the stress of childhood cancer (Chesler, 1984). In other cases, however, parents adopted individual coping patterns that eventually made life more difficult for one another (Barbarin, Hughes, & Chesler, 1985). Clearly, the relationship between parental coping styles and adaptation to pediatric cancer requires further study.

### Family System Resources

A number of scholars have suggested that certain family system resources may allow for more effective parental coping patterns, and thus enhance family adaptation to childhood cancer. Family system resources are the social-environmental characteristics or relationships in families. For example, Olson, Sprenkle, and Russell (1979) hypothesized that balanced families that are moderate on both dimensions of cohesion and adaptability will function more adequately and be better able to adapt to developmental and situational stress over the life cycle.

At least two studies have reported on the role of family system resources in parental adaptation in families with a chronically ill child. For parents of a child with cystic fibrosis, Venters (1981) found that the family's ability to share the burden of their child's condition, both emotionally and physically, and the idiosyncratic "meaning" they give to their child's illness influenced their adaptation. In a model based on interviews with parents and siblings of children with cancer in remission, Koch (1985) proposed that the presence of family rules which permit emotional expression and role flexibility will facilitate family adaptation to pediatric cancer. Although a few studies

have examined specific family system resources, no research reviewed used multivariate methods to determine their association with family stress and coping patterns in parental adaptation to childhood cancer.

#### STATEMENT OF THE PROBLEM

Although much is known about the hardships faced by parents of young people with cancer, it is not clear how they can best adapt. Three questions emerge from the literature:

1. Do family process stressors, family system resources, and parental coping patterns account for differences in parental adaptation to childhood cancer?

2. What dimensions of family process stressors, family system resources, and parental coping patterns are associated with parental adaptation to childhood cancer, and what are their overall relative contributions?

3. How are these dimensions related to each other?

If parents of children with cancer are primarily responsible for managing the illness and family life, information on resources for coping with family stress can aid them in their efforts to succeed.

The present study examined the relationships among family process stressors, family system resources, parental coping patterns, and parental adaptation to childhood cancer. Specifically, parents reported on their perceptions of: (1) the amount of conflict and control stress in their family environment; (2) their family resources and coping behaviors for dealing with the stress; and, (3) their current level of adaptation. These variables were examined to see which family stressor, resource, and coping factors were related to parental adaptation, and which could be used to predict that outcome. The regression model was:

Family Process Stressors

+ Family System Resources

+ Parental Coping Patterns

-> Parental Adaptation

#### SIGNIFICANCE OF THE STUDY

This study contributes to the purposes of basic science by advancing knowledge in three areas. These areas include family stress theory, psychosocial oncology research, and family therapy.

### Family Stress Theory

This study, conducted prior to the development of the Typology Model of Family Adjustment and Adaptation (T-Double ABCX) by McCubbin and McCubbin (1987), provided an opportunity to test selected components of the Double ABCX Model of Family Adaptation on parents who have a child with cancer. Earlier research using the model has focused on other chronic childhood illnesses or disabilities. In a recent review of 22 investigations on family stress, coping, and serious childhood illness, McCubbin (1987) found that 10 of these studies involved physical impairment conditions (e.g., cardiac and renal disease, epilepsy, spina bifida, cystic fibrosis, diabetes). Another 10 studies looked at mental/behavioral conditions (e.g., autism, mental retardation, youth affective disorders) and three examined multiple handicaps and disabilities. Only one study, in the data collection stage, involved children with cancer. In summary, although childhood cancer has been the subject of numerous investigations (Carpenter & Onufrak, 1985), very few studies have employed family stress theory as the conceptual framework.

### Psychosocial Oncology Research

The literature on the psychosocial aspects of childhood cancer has proliferated enormously over the past several years. However, an extensive review of this literature by Van Dongan-Melman and Sanders-Woudstra (1986) reveals that research on family responses to childhood cancer has rarely been conducted within a theoretical framework. As a result, a clear outline of the interrelationships between the problems experienced and ways of coping with them has not evolved.

The results from the present study, well-grounded in family stress theory, can benefit the field of psychosocial oncology in several ways. First, they can describe the types of intra-family stressors which may complicate parental adaptation to pediatric cancer. Second, they can offer insight into the important resources and strategies that parents use to cope with the impact of childhood cancer. Third, they can provide a conceptual framework which may be refined and replicated in future research on psychosocial oncology.

### Family Therapy

Family therapists have long recognized the importance of viewing the management of illness from a systems perspective (Kantor & Lehr, 1975; Minuchin,

Rosman, & Baker, 1978; Quinn & Herndon, 1982). This study will extend that premise by offering new insights for clinical intervention with families who have a child with cancer. Specifically, information on the the manner in which families with childhood cancer are structured (e.g., organization and control) and the interactional patterns of family members (e.g., cohesion, expressiveness, conflict) may contribute to the efficacy of treatment. Moreover, an understanding of the coping patterns employed by parents of children with cancer may enhance both clinical prevention and intervention efforts by family therapists and other health care professionals.

## CHAPTER 2

### REVIEW OF THE LITERATURE

Chapter Two explains how this study relates to previous work as recorded in the literature. It begins with a discussion of the theoretical framework for the study, namely, family stress theory. Then, for each variable in the study, relevant research is reviewed. Finally, the study hypotheses are presented.

#### Theoretical Framework

The conceptual framework for this investigation is family stress theory. Originally advanced by Rueben Hill (1949, 1958) as the ABCX family crisis model, this framework stated that:

A (the stressor event) -- interacting with B (the family's crisis meeting resources) -- interacting with C (the family's definition of the event) -- produce X (the crisis).

The major factors in Hill's original ABCX model focused primarily on pre-crisis variables in the family. Factor A, the crisis precipitating event or stressor, was defined by Hill (1958) as a "situation for which the family has had little preparation." Factor B, the family's crisis meeting resources, was summarized as the

"adequacy-inadequacy of family organization" (Hill, 1958). Factor C, the definition the family made of the event, referred to the family's subjective perception of the stressor, the hardships created by the stressor, and how the hardships affected the family. Factor X, the crisis, has been conceptualized as a continuous variable denoting the amount of disruptiveness, disorganization, or incapacitatedness in the family social system (Burr, 1973).

Keeping the original ABCX equation, Burr (1973) attempted to add clarity to several of Hill's more underdeveloped variables. He elaborated on Factor B, the family's crisis meeting resources, by describing it as the family's ability to prevent an event of change in the family social system from creating some crisis or disruptiveness in the system. He suggested a number of family resource variables which may influence family adjustment. These Factor B variables included: the amount of personal influence held by the family or its members, the amount of reorganization required (adaptability), and the amount of communication (expressiveness) between family members.

Following Hanson's (1965) lead, Burr (1973) also reconceptualized Factor X, the crisis or level of adjustment, to include the continuous variables of family

vulnerability (i.e., their ability to prevent the event of change from creating a crisis) and family regenerative power (i.e., family efforts "over time" to recover from a crisis situation).

For two decades, Hill's ABCX model remained fairly unchanged, and most articles on stress and the family used it as a frame of reference (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980). However, there was some criticism that Hill's model lacked dynamic post-crisis variables (e.g., additional life stressors and coping behaviors) occurring during the adaptation period (McCubbin et al., 1980).

#### The Double ABCX Model of Family Adaptation

The Double ABCX model of family adaptation, developed by McCubbin and Patterson (1983), expanded Hill's original framework to include several new post-crisis variables. Essentially, the Double ABCX model used Hill's original equation as its foundation and added post-crisis variables in an effort to describe: (aA) the "pile-up" of additional life stressors and changes over time which may make family adaptation more difficult to achieve, (bB) the critical psychological and social factors families call upon and use in managing crisis situations, (cC) the processes families engage in to

achieve satisfactory resolution, and (xX) the outcome of these family efforts to adapt.

In this study, the Double ABCX Model has been used to guide the conceptualization and selection of variables. While not attempting to test the complete model, four critical post-crisis variables in the framework will be examined to determine their relationship in families with childhood cancer. These variables, outlined in Figure 1, include family process stressors (aA Factor), family system resources (bB Factor), parental coping patterns (cC Factor), and parental adaptation (xX Factor). For each variable, a definition and relevant research is reviewed.

#### Family Process Stressors

In the Double ABCX Model, the aA Factor refers to the "pile-up" or accumulation of stressors, demands, and changes which occur in the aftermath of a major stressor such as death, natural disaster, or diagnosis of a chronic illness. Three types of stressors appear to contribute to this pile-up in the family system: (1) the initial stressor event with its inherent hardships, (2) normative family life changes which occur concomitantly, but may be independent of the initial stressor, and (3) family process stressors which are associated with the

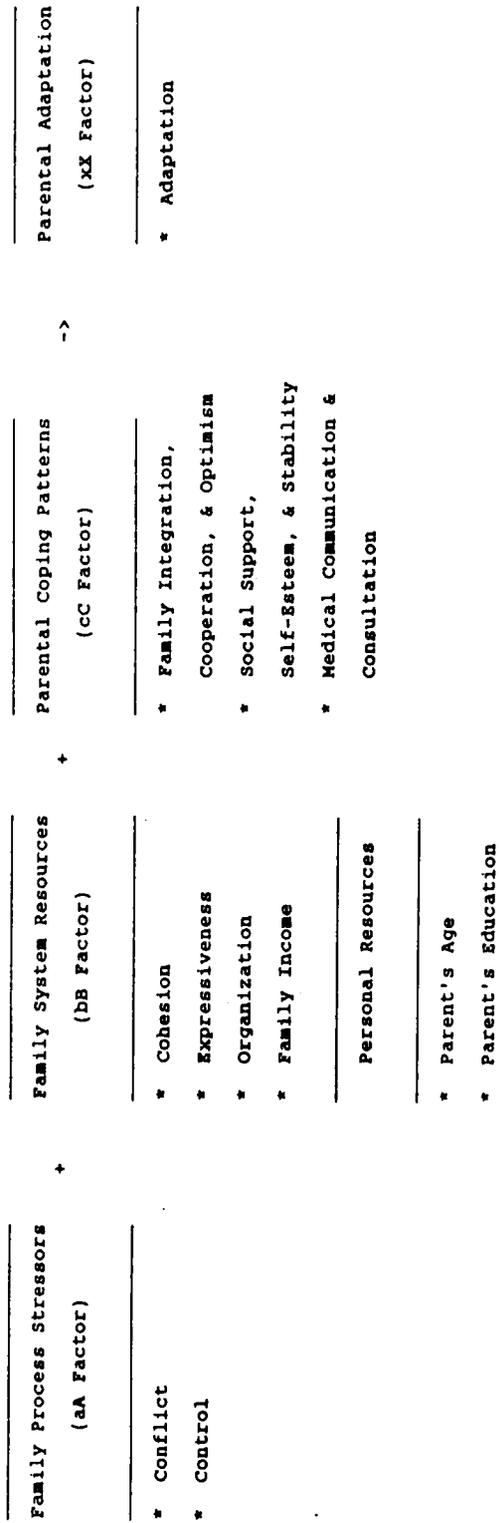


Figure 1. Regression Model for Parents

family's effort to cope with the hardships of the situation. The theory predicts that when these stressors are high, the level of disruption will be high, and the eventual recovery or level of family adaptation will be lowered. This study will focus on two family process stressors -- conflict and control -- which may impair parental adaptation to pediatric cancer.

### Conflict

The first family process stressor in this study is conflict. It refers to the amount of openly expressed anger, aggression, and conflict among family members in response to the stressor situation.

Conflict has been used as a measure of intra-family strain in several studies of the Double ABCX Model. For example, in the development of the Family Inventory of Life Events and Changes (FILE) instrument, McCubbin, Patterson, and Wilson (1982) included a 12-item conflict scale to reflect sources of tension and conflict between family members. They reasoned that intra-family conflict was a significant contributor to the pile-up of life events as well as a good index of family stress. As predicted, intra-family strains correlated negatively with the family system resources of cohesion (-.41), expressiveness (-.19), and organization (-.21)

and positively with conflict (+.42).

In studies on stress and coping in families of children with cancer, conflict has been associated with numerous family stressors. Chesler and Barbarin (1987) interviewed 95 parents of children with cancer and found that family conflict typically resulted from three key family stresses: (1) managing internal emotional relationships, (2) adapting to many new practical tasks, and (3) managing external relationships. No effort was made to compare families on these variables and conflict.

Family conflict has also been correlated with stressors in families with a chronically ill child. McCubbin and Patterson (1981) reported on discriminant analyses between low conflict families and high conflict families who had a child with cerebral palsy or spina bifida. They found that high conflict families, regardless of chronic illness, experienced a significantly higher pile-up of life changes in three areas: (1) intra-family strains, (2) work-family transitions and strains, and (3) total life changes.

In a study of the emotional quality of the home environment of employed married women, Abbott and Brody (1985) reported that conflict is higher for mothers with two children and mothers with male children when compared to mothers with one child and female children. Moreover,

the presence of two children in a household tended to increase family conflict, especially when excessive role demands were placed on mothers who were employed, as were the women in this study. The relationship between family conflict and excessive role demands has also been noted among fathers of children with cancer who work extra jobs to help the family cope financially (Northouse, 1984).

### Control

The other family process stressor to be examined in this study is control. Control refers to the extent to which set rules and procedures are used to run family life during the adaptation period.

Most of the research on control and childhood cancer has focused on the child patient. This is not surprising since almost all aspects of childhood cancer and its treatment have a major impact on control (Brunnquell & Hall, 1982). Because the disease requires constant medical care and attention, patients are confronted with increased dependence on others, loss of privacy, submission to hospital rules, restrictions on their way of life, and overprotection by parents. They must also permit invasive treatment procedures and accept the side effects.

From a systems perspective, the loss of control

experienced by the child with cancer will also be felt by other family members. Parents of children with cancer have reported problems related to a loss of control due to changes in the therapeutic schedules, changes in everyday life, difficulties in planning for the future (Nannis, Susman, Strobe, Woodruff, Hersh, Levine, & Pizzo, 1982), loss of financial resources (Cairns, Clark, Black, & Lansky, 1981), and loss of friends (Adams & Deveau, 1984). Although loss of control is closely related to uncertainty for these parents, it is a distinct aspect of their stress.

One parental response to such loss of control is to overcompensate in attempting to gain and maintain some control of the childhood cancer situation (Van Dongen-Melman, Pruyn, Van Zanen, & Sanders-Woudstra, 1986). For example, parents who are fearful of losing control of their own emotions may attempt to "control" the emotional climate of the family by overtly or covertly setting rules which prohibit the expression of emotions by others (Koch, 1985).

Efforts to control family life by adhering to established routines may actually undermine the parents' adjustment to their child's cancer. Barbarin, Hughes, & Chesler (1985) noted that the frequent hospitalizations, cost of medical care, vicissitudes of the child's

physical condition, and extended parental absences associated with childhood cancer often disrupt the entire family's ongoing routine. They found that flexibility in family routines and alterations in the parents' role definition were essential.

In general, when the rules and procedures used to run family life become overly rigid or insensitive to the developmental needs of the family or its members, control as a coping behavior becomes a family process stressor (McCubbin & Patterson, 1981).

#### Summary

In summary, family environments characterized by high conflict and rigid attempts to control family members are associated with poorer adjustment and less ability to deal with stress, especially when coping with a chronic childhood illness such as cancer.

#### Family System Resources

The bB Factor in the Double ABCX framework refers to the family system resources. These resources are the psychological, social, interpersonal, and material characteristics of individual members and the family unit. As such, these resources play a role in reducing tension, managing conflicts, and in general, meeting the

demands and needs precipitated by the child's cancer diagnosis and treatment.

Some family system resources are personal in nature. That is, they refer to the broad range of resources, qualities, and aids characteristic of individual family members which are available to others in need. These include financial (economic well-being) and educational (contributing to cognitive and problem-solving abilities) attributes (Pearlin & Schooler, 1978).

Other family system resources involve characteristics of the family unit. These resources refer to the intrafamilial dynamics and relationships which enable the family to function together while trying to adapt to stress. They include family integration or cohesion (Burr, 1973), expressiveness (Koch, 1985), and organization (Olson, Sprenkle, & Russell, 1979). The theory predicts that when the resources are high, the level of disruption will be low, and the eventual recovery or family adaptation will be enhanced (Burr, 1973).

Although family system resources are important, assessing them systemically can be a problem. Because of the many dynamics and interactions involved, a family system is more than the sum of its parts. Yet for practical reasons, system measurement is often limited to

asking individual family members to report on their perception of the family system. In this study, the family system variables of cohesion, expressiveness, and organization were measured using parental perceptions of each resource.

### Cohesion

The first family system resource in the study is cohesion. Sometimes referred to as family integration, cohesion is defined by Moos and Moos (1986) as the degree of commitment, help, and support family members provide for one another.

Cohesion has long been a factor in family stress theory (Burr, 1973; Hill, 1958; McCubbin & Patterson, 1981). In the latter work, McCubbin and Patterson suggested that family cohesiveness was strongly associated with the family strengths of esteem, communication, mastery, and health.

In research on families of children with cancer, cohesion has emerged as a significant variable. Koch (1985) interviewed the siblings and parents of 32 children with cancer to explore and describe their common experiences. Her qualitative data revealed five patterns of family reaction to the cancer. One of these patterns was an increased closeness among family members

(cohesion), which she predicted will vary in relationship to two other family system resources: expressiveness and rules permitting role flexibility.

Cohesion has also been shown to play an important role in family adaptation to other chronic childhood illnesses. Among parents who have a child with cystic fibrosis, high family cohesion was positively related to the use of problem-solving coping patterns (McCubbin et al., 1983). Families of handicapped children who were rated high on cohesion by interviewers showed more acceptance of and more competence in coping with the child (Bristol, 1984). Cohesive families also seemed to be better able to manage the strain of raising a child who had spina bifida cystica (Nevin, Easton, McCubbin, & Birkebak, 1979).

In general, these findings on cohesion are consistent with those of Olson, Lavee, & McCubbin (1989), who studied 1,140 couples and 412 of their adolescents in normal families throughout the United States to find out how families cope with stress across the life cycle. They reported that family cohesion was associated with relatively low levels of strain and high levels of a sense of well-being.

### Expressiveness

Expressiveness is the next family system resource examined in this study. It refers to the extent to which family members are encouraged to act openly and to express their feelings directly to one another (Moos & Moos, 1986).

Like cohesion, expressiveness has been a frequently cited resource in family stress theory. In expanding Hill's (1958) equation, Burr (1973) included the amount of communication between family members (expressiveness) as one of 15 family resources thought to influence family adaptation to crisis.

Expressiveness has been identified as a critical factor in family adaptation to pediatric cancer. Spinetta and Maloney (1978) found that children with cancer from families that openly discussed the illness had fewer problems and were more satisfied with themselves. Koch (1985), in her qualitative study of parents and siblings of children with cancer in remission, reported that rules permitting emotional expression (expressiveness) facilitated successful family adaptation to the illness. She concluded that, if families of children with cancer overtly or covertly prohibit the expression of emotions common to the experience (e.g., anger, guilt, fear, worry, sadness),

there will be an increase in health and behavior problems in the family.

In a study of home treatment of children with cystic fibrosis (Patterson, 1985), expressiveness was associated with more family compliance to the prescribed treatment. Patterson speculated that the open expression of concerns and feelings helps families appraise their situation realistically and manage it better.

### Organization

Organization is the third family system resource of interest in this study. It refers to the degree of importance of clear organization and structure in planning family activities and responsibilities (Moos & Moos, 1986). As such, this concept describes one aspect of the family's management of stress related to childhood cancer.

Organization, like cohesion, has long been a primary resource in the family's response to stress. In their longitudinal studies of the Depression, Cavan and Ranck (1936) and Angell (1936) found that well-organized families weathered even severe losses, while disorganized families suffered severe disruption. Koos (1946) reached the same conclusion after interviewing troubled tentament families in New York following the Depression. Later,

in developing his classic ABCX Model, Hill (1949, 1958) summarized Factor B (the family's crisis meeting resources) as the adequacy-inadequacy of family organization.

In studies relating to chronic childhood illness, organization has been positively associated with family adjustment. For example, Nevin (1979) found that well-organized, cohesive families were better able to handle the strain of raising a child who had spina bifida. Hauser and his co-workers (1985) reported that high organization was associated with perceived competence and adjustment to the illness among families of insulin-dependent adolescent diabetics. McCubbin and his colleagues (1983) noted the positive relationship between high family organization and the use of problem-solving coping patterns among parents of children with cystic fibrosis.

Surprisingly, the existing research on family adaptation to childhood cancer has not focused on organization per se. Koch (1985) described three patterns relating to role changes in her study of siblings and parents of pediatric cancer patients. However, these patterns -- patient-centered families, emotional caretaking families, and sibling maturation families -- appear to describe specific types of family

organization rather than degrees of organization and structure. Nonetheless, Koch's finding on the need for role flexibility in adapting to childhood cancer points to organization as a crucial family resource.

One interesting concept in the management of illness that relates to organization is Pratt's (1976) "energized family." This concept, derived from her analysis of health behavior in families, specifies the mechanisms that are available for promoting adaptation and positive change. Her "energized family" is viewed as a dynamic, fluid, internal organization in which role relationships and the distribution of power are flexible.

According to family therapists Quinn and Herndon (1986), flexibility in family organization is particularly important in families with cancer where the responsibilities of members may be unfairly and rigidly defined. In their example, "the mother may be burdened with caretaking responsibilities and work demands while the father works longer hours to avoid dealing with his fear, and the siblings of the patient 'walk on egg shells,' becoming less playful and more task centered" (p. 48).

#### Summary

These studies show the interaction between family

system resources and family process stressors. In general, well-organized, supportive families characterized by moderate to high cohesion and expressiveness and low conflict are able to adapt successfully to varied changes and demands. High family conflict and attempts to control, often the result of stress, are related to poor adjustment.

#### Parental Coping Patterns

In the Double ABCX Model, the cC Factor is family perception and coping. Family perception refers to the family's post-crisis efforts to redefine their situation in ways which will play a useful role in problem-solving and eventual adaptation. Coping refers to the cognitive and behavioral responses which are employed by the family members to manage the multiple demands of their situation (Lazarus, 1984).

Viewed in this way, the family's perception becomes an integral component of parental coping. In other words, the way in which parents "perceive" the stressor situation (e.g., as "a challenge" or "an opportunity for growth" or "a sign of God's revenge") will influence their coping responses to it. For this reason, parental coping patterns are discussed under the cC Factor in this study even though they may be

appropriately viewed as family system resources (bB Factor).

Current research on family stress and coping with a chronically ill child has emphasized three underlying coping patterns used by parents (Comeau, 1985; McCubbin, 1988; McCubbin, McCubbin, Patterson, et al., 1983; Patterson & McCubbin, 1983). These three factors, labeled parental coping patterns, are: (1) family integration, cooperation, and an optimistic definition of the situation; (2) maintaining social support, self esteem, and psychological stability; and, (3) understanding the medical situation through communication with other parents and consultation with the health care team. The Double ABCX Model predicts that, the greater the repertoire of coping behaviors, the better adaptation will be. Relevant research on each of these coping patterns follows.

#### Family Integration, Cooperation, and Optimism

One parental coping pattern commonly found in family stress research involves behaviors that focus on family relationships and the parents' outlook on life. Billings and Moos (1981) studied the role of coping responses and social resources in attenuating the stress of life events among a normal family sample. Two of the

top seven coping strategies they observed were related to optimism, that is, "Tried to see positive side" and "Didn't worry; figured everything would probably work out fine."

In research on families of children with cancer, family integration joins optimism as a helpful parental coping behavior. Christiansen (1982) reported that parents of children with cancer rated behaviors associated with family integration, cooperation and optimism as extremely helpful. Similarly, Kupst and associates (1982) described nine coping behaviors which they found to be common among parents of children with leukemia. These included "optimism" and "maintenance of normal family functioning." In her interviews with the parents and siblings of children with cancer, Koch (1985) observed that an increased closeness among family members was a significant coping pattern in her study of adaptation.

Parental coping behaviors related to family integration and optimism were also found to be extremely helpful by mothers and fathers of children with diabetes (Bode, 1983), cystic fibrosis (Gibson, 1984), and cerebral palsy (McCubbin & Patterson, 1983).

### Social Support, Self-Esteem, and Stability

Another common parental coping pattern in the family stress literature is maintaining social support, self-esteem, and psychological stability. Specifically, this pattern involves the parents' efforts to develop relationships with others, engage in activities which enhance feelings of individual identity and self-worth as well as behaviors to manage psychological tensions (McCubbin, McCubbin, Nevin, & Cauble, 1979).

Conceptually, many of the behaviors involved in this parental coping pattern have their roots in social support theory (Caplan, 1976; Cobb, 1976). This theory states that family members under stress relate to the community and to each other to obtain emotional, esteem, and network support.

Research on families of children with cancer reveals consistent evidence of the coping pattern of social support, self-esteem, and psychological stability. In their self-report study of parental coping one year after diagnosis, Kupst and her colleagues (1982) found that parents of children with leukemia emphasized open communication with significant others as helpful. More recently, Chesler and Barbarin (1987) summarized the family stresses and related coping strategies obtained from a random sample of 55 families of children with

cancer. Their list of coping strategies includes: "maintain marital intimacy" and "seek help from friends and relatives" as well as "withdraw from social contact" and "separate from others, keep feelings private, maintain distance" (p. 119). Apparently, strengthening of self through social support and increasing self-esteem is a parental coping pattern that requires a delicate balance between time alone and time with others.

In a sample of parents of children with cystic fibrosis, Gibson (1984) reported that mothers' coping efforts were more focused on family integration and social support, self-esteem and psychological stability than fathers'.

#### Medical Communication and Consultation

The last parental coping pattern examined in this study is understanding the medical situation through communication with other parents and consultation with the health care team. In addition to developing peer and medical relationships, this coping pattern involves increasing knowledge about the illness and mastering any home care treatments and medical regimens (McCubbin, McCubbin, Nevin, & Cauble, 1979).

On one level, this coping pattern involves behaviors directed at seeking information. According to

Van Dongen-Melman and associates (1986), when people feel uncertain about an illness, i.e., when they feel they lack information about it, they tend to consult formal sources such as the hospital medical staff or social workers, their family physician, books or television programs. In addition, people seek information from informal sources, such as other parents who are in a comparable situation (Comaroff & Maguire, 1981).

Several studies have documented that accurate information is a powerful method of reducing uncertainty and depression in families of children with cancer (Kellerman, Rigler, Siegel, & Katz, 1977; Slavin, O'Malley, Koocher, & Foster, 1982; Spinetta & Maloney, 1978). These findings would appear to support the adage that "Fear of the unknown is worse than fear of the known."

On another level, this coping pattern involves behaviors directed at seeking support and comfort. The idea that fellow stress victims can have positive effects on each other is supported in the literature advocating group sessions for parents of children with cancer (Knapp & Hanson, 1973; Koch, Hermann, & Donaldson, 1974; Stolberg & Cunningham, 1980).

In some situations, however, this coping pattern may provoke increased fear, sadness, and confusion among

parents of children with cancer. Kalnins, Churchill, & Terry (1980) studied the concurrent stresses in families with a leukemic child and found that, when parents compared their situation with one that was worse (e.g., when someone's child died), they reported an increase in stress and "negative emotions." On the other hand, Comaroff and McGuire (1981) found that parents of children with leukemia tended to select their information by emphasizing the similarities between their child and other cancer patients who appear to be doing well and by avoiding identification with those who have not responded well to therapy. Perhaps, the "communication with other parents" component of this coping pattern is a highly selective process.

In general, coping behaviors related to medical communication and consultation were found to be extremely helpful by parents of children with diabetes (Bode, 1983) and cystic fibrosis (Gibson, 1984).

#### Summary

Taken together, these studies support the Double ABCX Model prediction that families possessing a larger repertoire of coping behaviors will manage the situation of the chronically ill child more effectively. Whether this prediction holds true for parents of children with

cancer is one of the questions investigated in this study.

### Parental Adaptation

The xX Factor in the Double ABCX Model is family adaptation. As such, it is used to describe the outcome of family efforts to achieve a new level of balance in family functioning which was upset by the family crisis (McCubbin, McCubbin, Nevin, & Cauble, 1979). Since this study is primarily concerned with parental adaptation, the variable has been defined as the parents' perception of the extent to which they have successfully adjusted to the stressors, demands, and changes involved in managing family life since their child's cancer diagnosis.

The parental response to childhood cancer has received considerable research attention in recent decades. The literature on the psychosocial impact of pediatric cancer has grown from a few pessimistic reports in the 1960's (Hamovotich, 1964; Binger, Ablin, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969) to a multitude of more optimistic studies in recent years (Chesler & Barbarin, 1987; Northouse, 1984). This section will review selected studies which have described the relationship between childhood cancer, family psychosocial factors, and adjustment in the parent.

In an early study, Binger and his associates (1969) conducted retrospective interviews with 20 parents of children who had died of leukemia in order to elicit information regarding short-term and long-term effects upon the patient, parents, and siblings. They concluded that, in 50% of the families studied, at least one family member reacted so strongly to the crisis that he or she needed psychiatric help. Variables identified as crucial to the parent's recovery included: the initial reaction, coping methods, belief systems, relationships with friends, and current burdens and sources of support.

Unlike Binger et al., (1969), Spinetta and his research team (1974, 1979) collected data on family adaptation and pediatric cancer while the child with cancer was still alive. Using a three-dimensional dollhouse technique to operationalize the child's distancing from family members, Spinetta, Rigler, and Karon (1974) found that as children neared death, they placed parental and medical figures farther away from themselves. In a follow-up study 5 years later, Spinetta and Maloney (1979) administered the dollhouse technique with a 15-item measure of family communication and discovered that children and parents were closer together in families that discussed the child's illness openly. These so-called "dollhouse studies" supported

Burr's (1973) theory of the role of family communication in adaptation to a stressor event such as cancer.

Additional support for the family stress theory came when Morrow, Hoagland, and Carnrike (1981) used a 45-item, self-report questionnaire to assess the psychosocial adjustment of 107 parents attending a national convention for parents of children with cancer. They found that: parents whose child had died recently showed poorer adjustment than parents whose child was in treatment (pile-up stressors); parents over 30 years of age showed better adjustment than younger parents (personal resources); and, parents with a child in treatment showed higher adjustment the more they reported perceived social support (coping patterns).

In the first longitudinal studies of family adaptation to pediatric cancer, Spinetta and Deasy-Spinetta (1981) measured the parent's overall level of adjustment to their child's cancer using the Family Adjustment Scale (FAS) over time. The FAS assessed the extent to which the parents met the emotional, medical, and day-to-day needs of the patient, siblings, spouse, and self. Results showed that mothers adjusted better than fathers, and patients adapted better than their siblings. The emotional needs of the family members emerged as more important to overall adjustment than

medical or day-to-day needs.

Like Binger, et al. (1969) nearly two decades before her, Koch (1985) chose to interview parents directly about their adaptation to childhood cancer. Five family patterns emerged from her qualitative data: (1) increased experience of negative affect; (2) rules prohibiting emotional expression; (3) health or behavior problems appearing or becoming exacerbated following the diagnosis; (4) role changes; and, (5) increased closeness among family members. She concluded that family adaptation to pediatric cancer will be effective when two resources are present, i.e, rules permitting emotional expression and role flexibility.

#### Summary

The literature on family adaptation to childhood cancer has shown that some families maintain or increase their level of functioning, while others become disorganized and ineffective. For parents in these studies, effective adjustment to their child's illness appears to depend on family process stressors, personal and family system resources, and coping strategies. The present study will provide insight into how each of these variables interact to predict successful adaptation among parents of children with cancer.

### Hypotheses

Based on the literature, the following hypotheses are proposed.

1. There will be a positive relationship between family system resources (cohesion, expressiveness, and organization) and the parent's adaptation.

2. There will be an inverse relationship between the family process stressors (conflict and control) and the parent's adaptation.

3. There will be a positive relationship between parental coping patterns (family integration/optimism, social support/self-esteem, and medical information/consultation) and the parent's adaptation.

4. There will be a positive relationship between the demographic variables (parent's age, parent's education, and family income) and the parent's adaptation.

5. The family system resources of cohesion and expressiveness, and the parental coping pattern of family integration/optimism will be the best predictors of the parent's adaptation.

## CHAPTER 3

### METHODOLOGY

In Chapter Three, the research methods used in this study are described. The chapter begins with an explanation of the sample selection and a description of the participants. Next, the data collection procedures and instruments are described. Finally, the data analysis plan is presented.

#### Sample Selection

The sample for this study was drawn from parents who had a child with cancer who was being seen at periodic intervals at selected pediatric hematology-oncology centers in Virginia and North Carolina during the period between June 1, 1987 and October 1, 1987.

The centers used for sampling were located at the Bowman Gray School of Medicine, Wake Forest University, Winston-Salem, North Carolina; the Children's Hospital of the King's Daughters, Norfolk, Virginia; the Children's Medical Center of the University of Virginia, Charlottesville, Virginia; the Duke University Medical Center, Durham, North Carolina; and the Medical College of Virginia, Richmond, Virginia.

Criteria for inclusion in the study were that the family composition should include two parents living in the home, and that the child's cancer diagnosis should have occurred not less than 3 months and not more than 4 years prior to data collection.

One hundred twenty-five questionnaires were distributed, and 98 were returned (78% return rate). Of the 98, four questionnaires were dropped from the analysis due to missing data. Another four respondents (i.e., those residing in single parent homes) were excluded because they did not meet the selection criteria.

The remaining sample consisted of 90 parents (58 mothers and 32 fathers). This total, however, included responses from 24 couples. Since each parent responded individually to the questionnaire, the data from these couples created an overlap of respondents for 27% of the children with cancer in the sample.

Confronted with the statistically confounding overlap of parents and the low number of fathers in the sample, a preliminary comparison of the two groups was made. In order to determine whether mean differences between mothers and fathers were significant, one-way analyses of variance (ANOVAs) were used to compare the groups across all variables. The results revealed no

significant differences between the two groups, except on the variable related to the parental coping pattern of medical information/consultation ( $F = 8.01$ ,  $df = 1,88$ ,  $p < .01$ ). The sample fathers reported using this coping pattern more often than did the mothers.

A Pearson correlation was then obtained for mothers' and fathers' adaptation on each variable to determine any relationship between the dependent variable (adaptation) and coping-medical information/consultation for each group. The correlations for mothers' adaptation ( $r = -.02$ ) and fathers' adaptation ( $r = -.05$ ) on coping-medical information/consultation were similar and well within the range of no systemic relationship. Therefore, the groups were considered equal and, rather than attempting to survey the missing fathers or to recruit additional ones late in the study, the decision was made to restrict the analysis to the mothers' data. This reduced the total usable sample size to 58 mothers.

The option of increasing the sample size artificially by treating each member of the marital dyads as a separate subject was ruled out on statistical and conceptual grounds. Because the parents in question are members of the same marital couple, the statistical independence of their scores is debatable. Even if couples are conceptualized as social units, there must

be sufficient numbers of them in the sample to warrant dyadic analysis.

### Descriptive Analysis

Family, mother, and child characteristics of the total sample (N = 58) are summarized in Tables 1-3. In keeping with the selection criteria, two parent families comprised 100% of the sample. One foster parent family and one sister-as-parent family who had had long term care of the child with cancer were also included. The mean length of marriage was 12.4 years. The number of children in these families ranged from 1 to 8, with 50% having two children.

The average income for sample families fell between \$25,001 and \$35,000, with a range from less than \$5,000 per year to over \$45,000 annually. Over half of the respondents (55.2%) categorized their family's financial situation as "moderate problems but managing."

The average age for mothers in the sample was 34.7 years and ranged from 23 to 46 years, with half of the respondents (55.2%) between the ages of 30 and 39 years. The mean educational level for mothers was 12th grade, with a range from less than high school to completed graduate school. Forty-one percent of the mothers had high school diplomas, 20% had bachelor's degrees, and 10%

Table 1

Characteristics of Families in the Sample

Variable	<u>n</u>	%
Family Income		
Under \$5,000	2	3.4
\$5,000 - \$15,000	4	6.9
\$15,001 - \$25,000	15	25.9
\$25,001 - \$35,000	12	20.7
\$35,001 - \$45,000	9	15.5
Over \$45,000	16	27.6
Financial Situation		
No financial problems	19	32.7
Moderate problems but managing	32	55.2
Severe problems and struggling	7	12.1
Number of children		
One	4	6.9
Two	29	50.0
Three	13	22.4
Four	10	17.2
Five or more	2	3.5

Table 2

Characteristics of Mothers in the Sample

Variable	<u>n</u>	%
<b>Age</b>		
23 - 29 years	12	22.4
30 - 39	32	55.2
40 - 46	13	22.4
<b>Education</b>		
Less than high school	3	5.2
Finished high school	24	41.4
Completed some college	13	22.4
Finished college	12	20.7
Attended/completed graduate school	6	10.3
<b>Employment Status</b>		
Not employed	12	20.7
Employed part-time	10	17.2
Employed full-time	19	32.8
Full-time homemaker	17	29.3
<b>Race</b>		
Caucasian	51	87.9
Black	5	8.6
Native American	2	3.5
<b>Religion</b>		
Protestant	33	56.9
Roman Catholic	3	5.2
Jewish	0	0.0
Other*	22	37.9

\*Mothers in this category specified denominations such as Baptist (15.5%), Christian (5.2%), and Methodist (3.4%).

Table 3  
Characteristics of Children with Cancer in the Sample

Variable	n	%
<b>Gender of Child</b>		
Male	32	55.2
Female	26	44.8
<b>Age of Child</b>		
2 years	6	10.3
3 - 5	16	27.6
6 - 12	22	38.0
13 - 18	14	24.1
<b>Type of Cancer</b>		
Leukemia	32	55.2
Brain tumor	6	10.3
Lymphoma	3	5.2
Neuroblastoma	5	8.6
Wilm's tumor (kidney)	2	3.4
Soft tissue (muscle)	5	8.6
Bone tumor	3	5.2
Other	2	3.5
<b>Time Since Diagnosis</b>		
3 - 6 months	2	3.5
7 - 11 months	6	10.3
1 - 2 years	29	50.0
2 - 3 years	16	27.6
Over 3 years	5	8.6
<b>Currently in Remission</b>		
Yes	49	84.5
No	9	15.5
<b>Previous Relapse or Recurrence</b>		
Yes	12	20.7
No	46	79.3

had graduate degrees.

Regarding employment, one third of the sample mothers (32.8%) was employed full time outside of the home. Another 17% were employed part time. Twenty-nine percent of the mothers reported that they were full time homemakers, and 20% indicated that they were not employed at the time of the study.

The majority of the mothers (87.9%) were Caucasian. Other ethnic groups represented in the sample were Black (N = 5, 8.6%) and Native American (N = 2, 3.4%). Religious preference was predominantly Protestant (56.9%). Over a third of the mothers (37.9%) indicated "other" as their religion. This "other" category included specific Protestant denominations written in by the mothers, such as Baptist (15.5%), Christian (5.2%), and Methodist (3.4%). Only 5% of the mothers were Roman Catholic.

There was nearly an equal number of boys and girls (55.2% males and 44.8% females) with cancer in the sample. The greatest percentage of children (38%) was between 6 and 12 years of age. The mean age of the children was 8.5 years, with a range from 2 to 18 years.

Over half of the children in the sample (55.2%) had leukemia. The mean time since diagnosis fell between 1 and 2 years, with a range from 3-6 months to over 3

years. The majority of the children were in remission (84.5%) and most had never had a relapse or recurrence of the cancer (79%).

#### Data Collection Procedures

The data were collected by research assistants recruited from the health care staff at each of the five sampling sites and trained by the author. For the most part, data were collected during the child's regular clinic visit with the interviews conducted during the routine "waiting room" time period. First, parents were given a letter (Appendix A) explaining the study and requesting their voluntary participation. Second, parents who were willing to participate were asked to sign a consent form (Appendix B) and complete the questionnaire (Appendix C) during their clinic visit. Third, parents unable to complete the questionnaire during a clinic visit were given a stamped, addressed envelope and asked to return the questionnaire to the research assistant by mail.

All participants were informed as to the amount of time (20-30 minutes) the questionnaire would take to complete and assured of confidentiality in their responses. They were told that they could receive a summary of the results upon request.

### Instrumentation

The instruments used in this study were designed to measure the parents' perception of their: (a) family process stressors; (b) family system resources; (c) parental coping patterns used to manage family life and the care of the chronically ill child; (d) degree of adaptation since their child's cancer diagnosis; and, (e) family socio-demographic information. All of the instruments were incorporated into a single questionnaire.

#### Family Process Stressors and Family System Resources

The Family Environment Scale (FES) (Moos, 1974) is a 90-item, true-false instrument designed to assess the social environment of families along 10 salient dimensions (Moos & Moos, 1976, 1983). The FES yields 10 subscale scores that measure aspects of the interpersonal relationships, the personal growth emphasis, and the basic structure or "system" of the family.

Parents in this study were asked to complete 2 of the 10 FES subscales (18 items) as measures of their family process stressors. These subscales are: (1) Conflict (the amount of openly expressed anger, aggression, and conflict among family members); and, (2)

Control (the extent to which set rules and procedures are used to run family life). A sample item from the conflict subscale is: "We fight a lot in our family."

Parents were also asked to complete three FES subscales (27 items) as measures of their family system resources. These subscales are: (1) Cohesion (the degree of commitment, help, and support family members provide for one another); (2) Expressiveness (the extent to which family members are encouraged to act openly and to express their feelings directly); and, (3) Organization (the degree of importance of clear organization and structure in planning family activities and responsibilities). A sample item from the cohesion subscale is: "Family members really help and support one another." The full set of items is included in the questionnaire (Appendix C, pages 113 - 114 ).

The FES subscales have moderate to high internal consistencies (ranging from .67 to .78 Cronbach's alpha), acceptable test-retest reliabilities (ranging from .73 to .86), and average subscale intercorrelations of approximately .20 (Moos, 1974). These intercorrelations are important because they reveal that the subscales are measuring distinct, though somewhat related, dimensions in the family social environment. The construct validity of the FES subscales has been supported by trained

raters' judgements and numerous comparisons with other family inventories (Moos & Moos, 1986).

For this study, parents were asked to respond individually to the FES items. The individual parent score on each of the five family environment scales was used in the data analysis.

### Parental Coping Patterns

The Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Nevin, & Cauble, 1979) is a 45-item, self-report checklist designed to assess parents' perceptions of their response to the management of family life when they have a child member who is seriously and/or chronically ill. The checklist contains 45 specific coping behaviors such as "Getting away by myself" and "Talking over personal feelings and concerns with my spouse." The full set of items is included in the questionnaire (Appendix C, pages 110 - 112 ).

Parents in this study were asked to record how helpful, on a scale of 0 to 3, each coping behavior is in their particular family situation. Previous factor analyses of CHIP has revealed three underlying coping patterns. These patterns are:

- (1) Maintaining family integration, cooperation, and an optimistic definition of the situation. This

coping pattern is composed of 18 behavior items which center around doing things as a family unit, strengthening family relationships, and developing and maintaining a positive outlook on life in general and, specifically, when a member has a chronic illness. The normative reliability for this scale was .79 (Cronbach's alpha). A sample item for parents to rate is: (How helpful is) "believing that my child will get better?"

- (2) Maintaining social support, self esteem, and psychological stability. This coping pattern consists of 19 behavior items which focus on the parent's effort to maintain a sense of his or her own "well being" through social relationships, involvement in activities which have the potential of enhancing self esteem, and managing psychological tensions and strains. The normative reliability for this scale was .79 (Cronbach's alpha). A sample item for parents to rate is: (How helpful is) "going out with my spouse on a regular basis?"

- (3) Understanding the medical situation through communication with other parents and consultation with medical staff. This coping pattern involves eight behavior items which focus on relationships

developed with other parents who have a child with a similar illness and the relationship developed with the health care team. It includes behaviors directed at understanding and mastering medical information needed to care for the chronically ill child and use of the medical equipment at home. The normative reliability of this scale was .71 (Cronbach's alpha). A sample item for parents to rate is: (How helpful is) "reading more about the medical problem that concerns me?"

Validity assessments of CHIP were supported using the Family Environment Scale (Moos, 1976) and two indices of changes in the health of children with cystic fibrosis. Validation was also obtained doing a discriminant analysis between low conflict and high conflict families who had a child with cerebral palsy.

In this study, parents were asked to complete the CHIP individually. The individual parent score for each of the three coping pattern scales was used in the data analysis.

### Parental Adaptation

The dependent variable, parental adaptation to pediatric cancer, was measured by a modified version of the Family Adjustment Scale (Spinetta & Deasy-Spinetta,

1981), now referred to as the Parental Adaptation Assessment (PAA). The PAA is a 20-item, self-report measure which was designed to assess parents' perception of their degree of adaptation to the experience of having a child with cancer in the family. Parents were asked to rate, from 1 to 5, how well they adapted in 20 areas of family functioning since their child's cancer diagnosis. The scale of responses ranged from "Worse than before" to "Better than before" the diagnosis. The areas of family functioning included such items as "Keep up with household chores" and "Maintain the overall quality of my family life." The full set of items is included in the questionnaire (Appendix C, page 115 ).

The internal reliability of the PAA was substantial (Cronbach's  $\alpha = .90$ ) for this sample. In validity checks of the original FAS (Spinetta & Deasy-Spinetta, 1981), parental ratings of their family's adjustment to the cancer experience correlated highly (ranging from .41 to .85) with ratings made by their health care professionals. The expanded version (PAA) used in this study contains 10 additional items suggested by health care professionals at the various sampling sites.

In this study, parents were asked to respond

individually to the PAA items. The individual parent score on the adaptation scale was used in the data analysis.

#### Family Socio-demographic Information

In the last section of the questionnaire, parents were asked to provide some basic demographic information, e.g., gender, age, race, religion, education, income, and employment status. In addition, they were asked to respond to several questions about their child with cancer, e.g., gender, age, cancer type, time since diagnosis, remission and relapse status. The full list of items is included in the questionnaire (Appendix C, pages 116 - 118 ).

#### Data Analysis

Responses to questionnaire items were coded and entered into a computer program using procedures in the SPSS/PC+ (1986) system. Frequency distributions and percentages were used for the descriptive analysis.

To examine bivariate relationships (and to detect possible multicollinearity), a correlation matrix among the independent and dependent variables was calculated. Means and standard deviations for all variables

intercorrelated were also generated and reported in the same table.

Next, in keeping with the exploratory nature of the study, stepwise multiple regression procedures were used to investigate the hypothesized relationships between the independent and dependent variables. This analysis was conducted in three stages. First, related sets of independent variables (i.e., the family process stressors, the family system resources, the parental coping patterns, and selected socio-demographic variables) were examined for their ability to predict the dependent variable. Then, those variables that emerged from each of the "set" analyses as statistically significant at the .05 level or below were examined together in a separate regression analysis. Finally, the partial standardized regression coefficients of the best predictor variables were examined to determine their relative importance in accounting for the variance in the dependent variable.

This three-stage regression procedure is preferable to a single "overall" regression analysis when the independent variables are correlated among themselves, i.e., when any statement about an independent variable is contingent upon the other variables in the equation (Cross, 1987).

The level for inclusion of a variable in the equation was set at .05. Variables included in the regression analysis were measured at the interval level or could be treated as such, as in the case of a dichotomous nominal variable. The significance level for all findings and the minimum requirement for support of a hypothesis was set at .05.

Three additional analyses were done. First, because of modifications made in the instrument used to measure the dependent variable, reliability coefficients for the scales used in this study were calculated. Second, because of the low number of fathers in the sample population, a one-way analysis of variance procedure was used to compare mothers and fathers across all variables. Third, because of the exploratory nature of the study, a curvilinear regression analysis was conducted to detect any non-linear trends in the hypothesized relationships.

## CHAPTER 4

### RESULTS

The results for each hypothesis are described in this chapter. A table of correlations, means, and standard deviations for the independent and dependent variables is included. The regression analysis then follows.

#### Results

The descriptive characteristics of the families, mothers, and children in the study are summarized in Tables 1-3. As a whole, the sample can be described as being of middle socioeconomic status, Caucasian, Protestant, with two children. The complete descriptive analysis is reported in Chapter 3.

The zero-order correlations for both independent and dependent variables as well as the means and standard deviations for the mothers ( $N = 58$ ) are presented in Table 4. For the most part, the inter-correlations between variables are relatively low to modest. Those that are statistically significant would be expected given the nature of the variables. For example, one would expect that cohesion and organization would be positively correlated since the subscales measure

Table 4  
Correlations, Means, and Standard Deviations for the Independent and Dependent Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Conflict	--	.35**	-.55***	-.34**	-.31**	-.10	.20	-.03	-.14	-.03	-.16	-.21*
2. Control		--	-.37**	-.38**	.03	.05	.09	.26*	.10	-.13	.01	-.27*
3. Cohesion			--	.55***	.31**	.32**	.04	.00	.15	.03	.09	.51***
4. Expressiveness				--	.05	.25*	.11	.10	.21	.07	.10	.31**
5. Organization					--	.33**	.10	.05	.12	-.03	.15	.15
6. Coping: Family Integration						--	.59***	.54***	.11	-.12	-.07	.21
7. Coping: Social Support/Self-Esteem							--	.36**	-.13	-.06	-.20	.00
8. Coping: Medical Communication								--	.11	-.13	.07	-.01
9. Mother's Age									--	.26*	.56***	-.20
10. Mother's Education										--	.58***	.02
11. Family Income											--	.04
12. Adaptation												--
<u>M</u>	3.66	5.02	6.36	5.05	5.72	41.45	28.64	19.21	34.78	3.90	4.21	58.84
<u>SD</u>	2.02	1.68	2.49	2.06	2.02	6.27	8.15	3.59	5.80	1.12	1.45	12.44

\*p ≤ .05 \*\*p ≤ .01 \*\*\*p ≤ .001

distinct, though somewhat related, aspects of family social environment. Similarly, education and income typically show significant intercorrelations. Multicollinearity was not likely to be a problem with such modest intercorrelations.

### Hypothesis 1

There will be a positive relationship  
between family system resources  
(cohesion, expressiveness, and organization)  
and the mother's adaptation.

This hypothesis was partially supported by the study. Correlations between the family environment variables of cohesion, expressiveness, and organization and adaptation are included in Table 4. The more committed, helpful, and supportive mothers perceived their family to be (cohesion), the higher their scores on adaptation ( $r = .51, p < .001$ ). Similarly, the more mothers reported talking openly with their family members about feelings (expressiveness), the higher their scores on adaptation ( $r = .31, p < .01$ ). The low positive relationship between organization and mother's adaptation, however, was not significant ( $r = .15, p = .135$ ).

### Hypothesis 2

There will be an inverse relationship  
between family process stressors  
(conflict and control)  
and the mother's adaptation.

This hypothesis was supported by the data. As shown in Table 4, the correlation between conflict and adaptation was  $-.21$  ( $p < .05$ ) and between control and adaptation was  $-.27$  ( $p < .05$ ). The higher the mothers' scores on the conflict dimension of family environment (i.e., openly expressed anger, aggression, and conflict among family members), the lower their scores on adaptation. The more they reported setting rules and procedures to run family life (control), the lower their scores on adaptation.

### Hypothesis 3

There will be a positive relationship  
between parental coping patterns  
(family integration/optimism, social support/self-esteem,  
and medical information/consultation)  
and the mother's adaptation.

Correlations between the parental coping patterns and adaptation are given in Table 4. None of the parental coping relationships were supported by this

study. There was a low positive association between the mothers' scores on the coping-family integration/optimism variable and their scores on adaptation, however, the relationship was non-significant ( $r = .21$ ,  $p = .068$ ). Correlations between coping-social support/self-esteem and adaptation ( $r = .00$ ) and between coping-medical information/consultation and adaptation ( $r = -.01$ ) also showed essentially no linear relationship. These results differed from the comments of sampled mothers who emphasized their belief that it was important for them to "keep a positive outlook" and "talk to other parents of children with cancer" for information and support.

#### Hypothesis 4

There will be a positive relationship  
between the demographic variables  
(mother's age, mother's education, and family income)  
and the mother's adaptation.

This hypothesis was not supported by the data. As indicated in Table 4, the demographic variables of mother's age ( $r = -.20$ ), education ( $r = .02$ ), and family income ( $r = .04$ ) were not significantly associated with adaptation. In fact, on the mother's age variable, the non-significant relationship was in a direction opposite from that which was predicted ( $r = -.20$ ,  $p = .061$ ).

### Hypothesis 5

The family system resource variables of cohesion and expressiveness, and the parental coping pattern of family integration/optimism will be the best predictors of the mother's adaptation.

This hypothesis was only partially supported. A summary of the stepwise regression analysis in which all significant independent variables were included with adaptation as the dependent variable is presented in Table 5. Variables were included in the table if they met the criteria of (a) adding at least one additional percent to R Square and (b) having an overall significance level of F greater than .05 (SPSS/PC+, 1986).

In the regression analysis using adaptation as the dependent variable, two of the 11 independent variables -- cohesion and mother's age -- entered with a resulting multiple R of .58 indicating that 34% of the variance was accounted for by these variables.

Relative comparison of the two predictor variables using beta weights showed cohesion, a family system resource factor, to be the most important contributor to adaptation (beta = .554; F = 5.00; df = 2,55; p < .001). The mother's age was second (beta = -.285; F = -2.57; df = 2,55; p < .05) in predictive strength.

Table 5

Multiple Regression Summary Table for Mother's Adaptation

Independent Variable	b	Beta	Zero-Order Correlation
Cohesion	2.766	.553	.51
Mother's Age	-.611	-.285	-.20
(Constant)	62.500		
<hr/>			
Multiple R = .584	(F = 14.21, df = 2,55, p < .000)		
R Square = .341			

The hypothesized variables of expressiveness and coping-family integration/optimism failed to meet the inclusion criteria and were not found to be significant predictors of mother's adaptation.

As a final check, a curvilinear regression analysis was conducted to determine whether the regression of the dependent variable (adaptation) on the independent variables was linear or curvilinear. No significant trends were observed in the data. Therefore, it was concluded, as predicted, that a linear regression model best fits these data.

## CHAPTER 5

### SUMMARY AND DISCUSSION

The final chapter provides a summary and discussion of the results of this study. Implications of the findings for each major variable in the study are summarized. The findings refer to the mothers' perception of the variables discussed even though this may not be specified in each instance. Next, the study's contributions to theory, research, and practice are described. The chapter concludes with recommendations for future research.

#### Findings Related To Family Process Stressors

There were significant negative correlations between the amount of family conflict and control stress perceived by the mother and her score on adaptation. This supports the family stress hypothesis of McCubbin, Patterson, and Wilson (1981) that the accumulation of intra-family strains following a crisis has an impact upon the family's level of adaptation.

Although these data are correlational, they appear to suggest that specific family process dynamics may become stressors in the aftermath of a child's cancer diagnosis. As an example of this, one mother wrote on

her questionnaire that "a lot of tension builds up. You try not to explode in front of the children, but sometimes you just can't help it. We seem to fight more now." In many ways, this comment typifies how parental coping efforts may become additional family stressors which make adaptation more difficult. Programs for parents and children with cancer should consider not only the major stressor event, but the ongoing family process strains related to conflict and control.

#### Findings Related To Family System Resources

As predicted, a strong positive correlation was obtained between family cohesion and the mother's adaptation. This finding supports the work of Koch (1985), McCubbin et al. (1983), and Nevin et al. (1979) which identified cohesion as an important factor in successful adaptation to chronic childhood illnesses. Data from this study would seem to indicate that, when considering vulnerability to the experience of childhood cancer, the level of family cohesion is crucial.

The family system resource of expressiveness was also significantly correlated with mother's adaptation. This result supports the more qualitative findings of Koch (1985) which concluded that rules permitting emotional expression are positively associated with

successful family adaptation to pediatric cancer.

In contrast to previous findings (Hauser et al., 1985; McCubbin et al., 1983; Nevin, 1979), organization was not significantly associated with higher scores on mother's adaptation. Several explanations for this seem possible. First, the operational definition of organization used in this study may be conceptually incapable of assessing the dynamic or "fluid" quality of family organization found in Pratt's (1976) "energized families." Pratt measured organization by asking family members about role relationships and the distribution of power in the management of stress. "Energized families" were characterized by flexible roles and shared power, as when parents move in and out of caregiving responsibilities. In the present study, a role flexibility scale may have provided a more precise, and perhaps significant measure of family organization.

Differences in men's and women's sex role socialization also may have influenced the mothers' responses toward organization. Women who have traditionally performed the expressive, integrative functions in the family may view high expressiveness as more important than organization in optimal family functioning. Patterson and McCubbin (1983) found that wives played an important role in encouraging family

expressiveness in families with a chronically ill child, whereas the husbands' role included maintaining organization in the family by minimizing the open expression of anger and aggression.

Taken together, the present findings support Anderson's (1986) suggestion that future research and theory building efforts should take into account the contrasting needs and perceptions of different family members, especially mothers and fathers.

#### Findings Related To Parental Coping Patterns

The correlations between parental coping patterns and mother's adaptation were all non-significant at the .05 level. These results do not support the earlier research of Christiansen (1982), Kupst, Schulman, Honig, Maurer, Morgan, & Frochtman (1982), and McCubbin and Patterson (1983). Those investigators reported that various parental coping strategies were extremely helpful in managing family life with a chronically ill child. Possible explanations for this discrepancy will be discussed for each coping pattern.

The parental coping pattern related to maintaining family integration, cooperation and optimism is noteworthy. Scores on this scale were positively associated with scores on mother's adaptation, but not

significantly so ( $p = .068$ ). This lack of significance may be due to the relatively small sample size in the study. Statistically nonsignificant results with trends in the expected direction are sometimes proven significant with an increased sample size (SPSS-PC+, 1986).

It was unexpected that the parental coping pattern involving the mothers' efforts to develop social support, enhance self - esteem, and maintain psychological stability was not associated with higher scores on their adaptation. One explanation may be that parents employ different coping patterns at different stages of their child's illness. Coping was measured at one point in time and generally at a more stable period of the child's condition (i.e., over 75% of the children had been diagnosed 1-3 years prior to data collection and were currently in remission). It may be that the coping pattern related to social support, self-esteem, and stability is used more by mothers during the highly stressful periods following diagnosis, when the child's condition deteriorates or is in a terminal phase. Future research using longitudinal measures would help to document and clarify Hill's (1958) concept of the family's "roller coaster course of adjustment" to chronic stress.

While some researchers have been able to identify this coping strategy as positively associated with parental adjustment (McCubbin, et al., 1981), these associations have not been strong. Barbarin and Chelser (1984) found no relationship at all. Perhaps, as Shapirio (1989) suggests, successful adaptation depends more on the parents' assessment or perception of their efforts rather than on any single coping pattern per se.

It was also interesting that the parental coping pattern directed at developing relationships with medical professionals and other parents of children with cancer was not associated with higher scores on mother's adaptation. Several explanations for this seem possible. First, as previously noted, the literature on social support and parents of children with cancer suggests that contact with parents of other patients has the potential for increased anxiety and fear as well as for comfort and support (Comeroff & Maguire, 1981; Kalnins, Churchill, & Terry, 1980). Since the majority of the children in this sample were in remission (84.5%) and had never had a relapse or recurrence of the cancer (79%), the mothers studied may have felt less of a need or desire to cope by consulting with health care professionals or communicating with other parents whose children may not be responding well to therapy. Second, the mothers' use

of this coping pattern may be related to gender or marital relationship factors. In the preliminary ANOVAs comparing mothers and fathers in this study, the only significant difference found between the two groups was that the fathers reported using the medical communication/consultation coping pattern more than the mothers did. Since there were 24 couples represented in the sample, this difference may reflect Barbarin, Hughes, and Chesler's (1985) finding that spouses adopt complementary coping styles with respect to problem-solving and their child with cancer. Further research is needed to determine the role of the child's health and the spouse's coping behavior on mother's adaptation.

In summary, although none of the statistical associations in this study were significant for parental coping patterns and mother's adaptation, taken together they point toward some important implications for professionals in the field of childhood cancer.

#### Findings Related To The Regression Model For Mother's Adaptation

Results from this study appear to indicate that family cohesion and mother's age are significant factors in explaining the variance in overall adaptation among mothers of children with cancer. Cohesion, a family

system resource, refers to the degree of commitment, help, and support family members provide for one another. The positive relationship between cohesion and adaptation would suggest that as family supportiveness increases, this may have a positive effect on the mother's adaptation. This supports family stress theory by suggesting that family system resources help mothers manage the multiple demands of their child's cancer condition.

Age of the mother also accounted for a significant proportion of the variance in her overall adaptation level. The inverse relationship between mother's age and her adaptation would suggest that as the mother's age increases, this may have a negative effect on her perceived adaptation. Since this finding was contrary to what was predicted under family stress theory, the mother's age variable requires some speculation.

A higher age for mothers corresponded to a lower adaptation score. One possible explanation is that older mothers may have more traditional roles established because of habit or cultural value than younger mothers. If so, they may find some of the resources for adaptation, e.g., expressiveness and role flexibility (Koch, 1985), less attractive. A second explanation involves the number of children in the family. The older

mothers tended to have more children at home, in addition to the child with cancer, thus increasing the demands on their resources for adaptation. Abbott and Brody (1985) found that the presence of two or more children in a household tends to increase family conflict and lower cohesion, especially in families where the mother is employed. In this study, there were significant positive correlations between mother's age and number of children. Further analysis of these data may reveal additional insight into this relationship.

Although cohesion and mother's age were found to account for significant proportions of mother's adaptation, it was surprising that the other predictor variables failed to enter the regression equation. Several of these factors, such as expressiveness and parental coping related to family integration and optimism, have explained variance in other models of family adaptation (Koch, 1985; McCubbin & Patterson, 1983). An accurate interpretation of this is somewhat unclear; however, the mothers' assessment of their own adaptation may help to provide one explanatory hypothesis.

When asked to rate their overall adjustment to pediatric cancer (Appendix C, Part C, item 20), most mothers in the sample reported that they had adapted

reasonably well. Of the 58 mothers studied, only seven (12%) rated the quality of their family life as worse than before their children's cancer diagnosis; three (5.2%) rated it somewhat worse than before. Almost half of the sample mothers (46.6%) felt the overall quality of their family life was the same as before the diagnosis, while 24% assessed it as somewhat better than before, and 12% better than before. Taylor (1983) notes that when individuals in stressful situations are asked how they are doing, most report that they cope well. It could be that parents of children with cancer compare themselves with others who are less well off, and imagining the worse case scenario, rate themselves as "above water!" This tendency for parents to present themselves as "up" to researchers, friends, and medical staff has been observed in other childhood cancer studies (Chesler & Barbarin, 1987; Kupst et al., 1982). For mothers in this study, successful adaptation may have meant that they are doing "better than others" or "as well as can be expected" even though their lives may still be stressful. If so, these varied conceptions of adaptation may have hurt the validity of the adaptation scale and thus, influenced the measurement and significance of predictive relationships. Further research using multiple measures of adaptation with established validity could help test

this hypothesis.

Other variables have been suggested in previous work that could be added to the regression model for mother's adaptation to increase the amount of explained variance. These factors include: the pile-up of stressful family life events or changes since diagnosis (McCubbin, 1988); the severity of the child's illness or number of active health problems (Comeau, 1985); the parents' assessment of marital functioning (Barbarin, Hughes, & Chesler, 1985); and the parents' perception of the difficulty or "personally significant meaning" of their situation (Venters, 1981). Although not documented in the literature, parent comments in this study would suggest that some measure of spiritual beliefs and/or religious supports might be highly predictive of adaptation.

#### Contributions To Theory

There are some interesting theoretical implications which emerge from this study. First, unlike most previous research on families and childhood cancer, this study was conducted within a theoretical framework. Second, the findings support the use of the Double ABCX Model of Family Adaptation as framework for understanding the relationships between post-crisis variables and

parental adaptation to pediatric cancer. Specifically, the results of this study showed that the best predictor of mother's adaptation was family cohesion, suggesting that when the family members are perceived as committed, helpful, and supportive of one another, the mother has a better sense of adaptation to her child's illness. This finding supports the inclusion of family system resources as mediators of stress in family stress theory (Burr, 1973; Hill, 1958, 1949; McCubbin & Patterson, 1983).

The emergence of mother's age as a significant, although relatively weak predictor of adaptation requires further theoretical attention. Within the Double ABCX model, should parental age continue to be viewed as a personal resource implying an "older and wiser" ability to cope with stress, or is increasing parental age another type of pile-up stressor which can offset the benefits of experience? The inverse relationship found between mother's age and adaptation in this study seems to support the second conceptualization. However, as will be discussed later, caution must be exercised in interpreting these data since mothers in this sample may not be representative of all mothers of children with cancer. Nonetheless, future theory building efforts should consider the age and accompanying developmental tasks of each family member for a more systemic picture

of adaptation (Hauser, Jacobson, Wertlieb, Brink, & Wentworth, 1985; Minuchin, Rosman, & Baker, 1979; Reiss & Oliveri, 1980).

This study also lends support to the recent emphasis on the convergence of theoretical frameworks such as the Double ABCX Family Stress Model and the Circumplex Model of Marital and Family Systems in order to better understand and explain predictors of family adaptation to stressful events (Lavee, 1985; McCubbin, 1988). Cohesion, the strongest predictor of mothers' adaptation in this study of the Double ABCX Model, is also a key dimension in the Circumplex Model which predicts that families who have moderate levels of cohesion and adaptability will function more adequately during stress over the life cycle (Olson, 1986). By combining the two theoretical models, a clearer picture may emerge about the nature of cohesion and its relationship to adaptability in different types of families.

#### Contributions To Research

One of the goals of this study was to examine the relationships among family process stressors, family system resources, parental coping patterns, and parental adaptation to pediatric cancer in a sample of mothers.

Before discussing the contributions of this effort, several methodological limitations need to be addressed.

The present research may be limited in that the Parental Adaptation Assessment (PAA) scale is a new, modified version of the Family Adjustment Scale (Spinetta & Deasy-Spinetta, 1981). As such, it is still in its formative stages in terms of establishing its credibility.

In addition, the sample was comprised exclusively of mothers from primarily intact, two-parent families, thereby limiting the representativeness of the sample in the general population. Factors such as marital status, perception of spousal support, congruence of parental coping styles, and assessment of marital functioning may have an impact on the process of adaptation (Barbarin, Hughes, & Chesler, 1985), thereby confounding the relationship between the independent variables studied and mother's adaptation.

An additional confound may be present in that the instruments used in this study assessed only the mother's perception of her adaptation at a single point in time. Some respondents may view their situation differently than other family members and may use different coping patterns over the course of their child's illness.

Despite these limitations, the study made several

important contributions to the field of psychosocial oncology. First, it confirmed previous findings that family cohesion is a significant predictor of parental adaptation to chronic childhood illness by using a sample of mothers who had a child with cancer. Second, it raised the possibility that the mother's age and number of children may be important variables to consider in future research on adaptation. Third, it described two intra-family process stressors -- conflict and control -- which were negatively associated with the mother's adaptation. Fourth, although no significant associations were found, it examined parental coping behaviors and adaptation in a clear conceptual framework which can be refined and replicated in future studies of childhood cancer.

These results are also intriguing from a methodological perspective. Unlike most previous work in psychosocial oncology, this study included in its sample five different pediatric hematology-oncology centers in two states. This selection process has its drawbacks, but allowed the researcher to obtain a more diverse cross-section of parents and minimize the potential bias in single-clinic studies (Northouse, 1984). In addition, this study responded to criticism of previous research designs in psychosocial oncology by

attempting to incorporate a time dimension into the measurement of parental adaptation. Mothers were asked to rate how well they adapted in various aspects of family functioning on a 5-point scale ranging from "Worse than before" to "Better than before" the child's diagnosis. This innovation may be more useful in assessing important areas of change than are the traditionally stated Likert scales.

Overall, the present study has provided a useful conceptual framework (Double ABCX Model) and a significant predictor variable (family cohesion) to the literature on parental adaptation in psychosocial oncology. Further studies, using more sophisticated designs, are necessary to determine a more precise relationship among the other variables in the model. One promising theoretical framework is the Typology Model of Family Adjustment and Adaptation (McCubbin & McCubbin, 1987). Developed as an expansion of the Double ABCX Model, the "T-Double ABCX" incorporates the role of family types in buffering the impact of stressful life events and facilitating family adaptation.

#### Contributions To Practice

The major contribution of this study to practice has been in the identification of family groups at risk

of ineffective parental adjustment. The results suggest that families which are low on cohesion may tend to be low on parental adaptation. These results may help the individual practitioner identify potentially problematic situations. For example, therapists who see a family with a child experiencing cancer could easily administer the questionnaire items related to cohesion and plan their interventions around the family members' responses.

In addition, clinicians and health care educators can use the findings of this study related to family process stressors and family system resources to sensitize themselves and their clients to problems associated with high conflict and control and low cohesion and expressiveness in pediatric cancer families. Such information may be useful in planning and implementing preventive measures.

Beyond the level of the individual practitioner, results from this study provide a useful knowledge base for identifying needed services and programs. For example, special counseling or support group services might be developed for mothers of children with cancer who are older, employed outside the home, and caring for more than one child.

Given the importance of family cohesion in

predicting parental adaptation, educational programs and literature could be made available to family members on effective ways to communicate support, helpfulness, and commitment to one another without becoming overprotective or controlling.

Although the relationships between parental coping patterns and mother's adaptation were not significant in this study, practitioners may want to carefully assess the stresses and resources of the family with childhood cancer before recommending specific coping strategies. For example, advice to "join a support group" or "develop an optimistic definition of the situation" may help some parents adapt but hinder others.

A final implication of the present findings is the need for practitioners to consider the differential effects that their interventions may have on mothers and fathers of children with cancer. For instance, encouraging greater emotional expressiveness between family members may be related to higher adaptation for mothers but not for fathers. Bowen (1978) suggested that men are more likely to view extreme expressiveness as "overreactivity" and "emotionality" rather than as helpful behaviors. Moreover, Russell, Atilano, Anderson, Jurich, & Paff-Bergen (1984), found that wives responded more favorably to less active interventions such as

reframing and actualizing current transactional patterns, while husbands responded more favorably to active interventions such as restructuring dysfunctional subsystem boundaries and firming up appropriate boundaries. Until further research examines the father's adaptation process and explores the possibility of complementary roles in parental coping, practitioners should refrain from assuming that all parents of children with cancer respond alike.

#### Recommendations For Future Research

Additional research in this area must address several concerns. First, the limitations of the present study must be overcome in order to extend the results. These limitations include a small and homogeneous subject group, the use of self-report measures from one family member to ascertain complex relational variables, the lack of a longitudinal design, and the possibility of varying conceptions of "parental adaptation" which might lead to unreliable or invalid results.

Overcoming these limitations opens up numerous research possibilities. Most important to the present author are studies which will (a) use a developmental or longitudinal design, (b) collect data on relational issues from several family members, and (c) examine the

parents' subjective definition of their situation. Each of these recommendations has existing support in the literature.

Further research is needed to test the hypothesis that parental adaptation to childhood cancer is a process which develops and changes over time. Parental comments in this study emphasized how their coping strategies evolved and changed, often in response to their child's condition. Several authors have reported that specific problems are associated with each phase of childhood cancer (Slavin, 1981; Spinetta & Deasy-Spinetta, 1981). As a result, parental coping behaviors during the initial phase of the illness may differ from those that are helpful when the child is in remission, suffers a relapse, or enters the terminal phase (McCubbin, 1987).

Additional research using a developmental model or longitudinal design could measure parental coping behaviors at different points in the course of their child's illness. Other studies might measure parental coping before and after clinical interventions to improve coping behaviors. Johnson (1988) describes some promising panel analysis techniques which may prove helpful in designing such research.

Another important focus for future research is the measurement of relational issues in the parental

adaptation process. This study demonstrated the importance of family cohesion and expressiveness in the mother's adaptation. In addition, family conflict and control were negatively associated with her adjustment.

Future studies, however, may get a more systemic picture of how these relationship variables interact by collecting data from several family members. For example, measurement of both parents' perceptions of family stressors and resources would seem to yield important similarities and differences. Data obtained from the siblings and child with cancer would also enhance the interpretation of such complex "family" variables as organization, role flexibility, and control. Peyrot, McMurray, and Hedges (1988) provide a good example of research at the family level of analysis which focuses on relational measures in the family's response to illness.

Finally a need for research which examines the parents' subjective definition of their situation has been noted. Although perception is included in the Double ABCX Model, it was not measured directly in this study. It may be that additional variance in parents' overall adaptation to childhood cancer could be explained by investigating the relationship between their

subjective perceptions of life with a chronically ill child and quality of family functioning. Kupst et al. (1983) and Venters (1981) both noted the contribution of the subjective data to interpreting the meaning of more objective measures. Further research is needed to see if the significant family variables in this study are related to the parents' subjective outlook and how this affects their adaptation.

The strongest recommendation for further study is to continue to search for those factors which explain how parents of children with cancer adapt most effectively. The present study used the family stress framework and identified cohesion, a family system resource, to be a significant predictor of mother's adaptation. Additional research is needed to better understand family resources and adaptation and how to assist parents in managing the impact of childhood cancer over time.

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APPENDIX A

Letter To Parents Explaining The Study  
And Requesting Their Participation

Dear Parents:

The Pediatric Hematology-Oncology Section here at the \_\_\_\_\_, along with other pediatric oncology centers such as those at \_\_\_\_\_ and \_\_\_\_\_, has been asked to participate in a study for a doctoral dissertation. We have agreed that the parents of our patients may be approached about participating in this study.

The purpose of this study is to gather information to better understand how families cope with the difficulties of having a child with cancer. If you are willing to participate in this study, we would ask that you sign the Consent Form and fill out the attached, brief questionnaire.

We want to emphasize that your child's care here in our clinic is in no way affected by whether you agree or decline to fill out the questionnaire. In either case, your responses will be confidential.

Should you have any questions you would like answered before agreeing to participate, we would be happy to answer them. You may also contact James R. Huber, M.S., the Doctoral Candidate coordinating this study, at (703) 989-6879 in the evening with questions about the study.

If you are interested in receiving a summary of the final report of this study, whether you complete the questionnaire or not, please let us know.

Sincerely,

\_\_\_\_\_, M.D.  
Director of Pediatric  
Hematology-Oncology

James R. Huber, M.S.  
Research Coordinator  
Virginia Tech

APPENDIX B

Consent Form For Parents

CONSENT FORM

I understand that the purpose of this study is to learn more about the factors which help families cope with childhood cancer.

I confirm that my participation as a subject is entirely voluntary. No coercion of any kind has been used to obtain my cooperation.

I understand that I may withdraw my consent and terminate my participation at any time during the investigation.

I have been informed of the procedures that will be used in the study and understand what will be required of me as a subject.

I understand that all of my responses, written or oral, will remain completely anonymous.

I understand that my child's treatment will not be affected by my decision to participate or not.

I wish to give my cooperation.

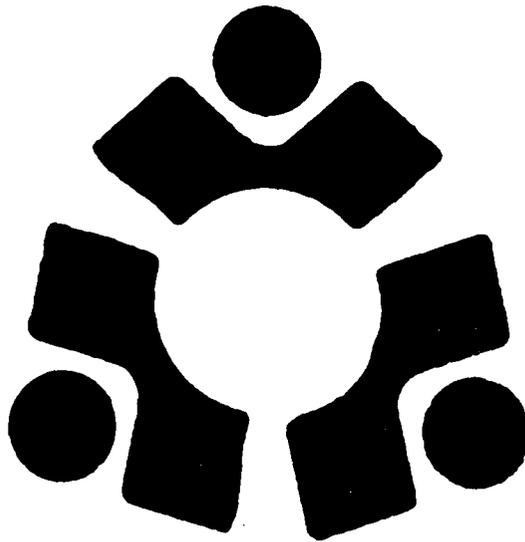
Signed: \_\_\_\_\_

Date: \_\_\_\_\_

APPENDIX C

Parent Questionnaire

# PEDIATRIC CANCER AND THE FAMILY



Department of Family and Child Development  
Virginia Polytechnic Institute and State University  
Blacksburg, Virginia 24061

in conjunction with

- . Bowman Gray School of Medicine, Winston-Salem, NC
- . Children's Hospital of the King's Daughters, Norfolk, VA
- . Children's Medical Center of the University of Virginia, Charlottesville, VA
- . Duke University Medical Center, Durham, NC
- . Medical College of Virginia, Richmond, VA

Dear Parent:

We realize you are a busy person, but we need your help.

This study is one of several we are doing to better understand the factors which help families cope with childhood cancer.

Your responses to this brief survey will enable us to find more effective ways to help families adjust to the demands of the illness.

Please answer all of the questions. Your answers will be kept anonymous and confidential. If you wish to comment on any items, please feel free to write in the margins or use the space provided on the back cover. Your comments will be read and taken into account.

Thank you for your help.

PART A

Parents of children with cancer cope in many ways. We want to understand which ways are most helpful. For each of the coping behaviors below, please CIRCLE the number indicating HOW HELPFUL it has been to you since your child's diagnosis. Please consider your family to be those persons living in your home as well as those to whom you have a long-term commitment.

(Circle number)

COPING BEHAVIORS	<i>Extremely helpful</i>	<i>Moderately helpful</i>	<i>Minimally helpful</i>	<i>Not helpful</i>	<i>Not used at all</i>
1. Trying to maintain family stability.....	3	2	1	0	NU
2. Engaging in relationships and friendships which help me feel important and appreciated	3	2	1	0	NU
3. Trusting my spouse or partner to help support me and our children .....	3	2	1	0	NU
4. Sleeping .....	3	2	1	0	NU
5. Talking with the medical staff (nurses, social worker, etc.) when we visit the doctors/clinic .....	3	2	1	0	NU
6. Believing that my child will get better ....	3	2	1	0	NU
7. Working, outside employment .....	3	2	1	0	NU
8. Showing that I am strong .....	3	2	1	0	NU
9. Purchasing gifts for myself and/or other family members .....	3	2	1	0	NU
10. Talking with other individuals/parents in my same situation .....	3	2	1	0	NU
11. Taking good care of all the medical equipment at home .....	3	2	1	0	NU
12. Eating .....	3	2	1	0	NU

		(Circle number)				
		<i>Extremely helpful</i>	<i>Moderately helpful</i>	<i>Minimally helpful</i>	<i>Not helpful</i>	<i>Not used at all</i>
COPING BEHAVIORS						
13.	Getting other members of the family to help with the chores and tasks at home .....	3	2	1	0	NU
14.	Getting away by myself .....	3	2	1	0	NU
15.	Talking with doctor(s) about my concerns about my child with cancer .....	3	2	1	0	NU
16.	Believing that the doctors/clinic/hospital has my family's best interest in mind .....	3	2	1	0	NU
17.	Building close relationships with people ...	3	2	1	0	NU
18.	Believing in God .....	3	2	1	0	NU
19.	Developing myself as a person .....	3	2	1	0	NU
20.	Talking with other parents in the same type of medical situation and learning about their experiences .....	3	2	1	0	NU
21.	Doing things together as a family (involving all members of the family) .....	3	2	1	0	NU
22.	Investing time and energy in my job .....	3	2	1	0	NU
23.	Believing that my child is getting the best medical care possible .....	3	2	1	0	NU
24.	Entertaining friends in our home .....	3	2	1	0	NU
25.	Reading about how other persons in my situation handle things .....	3	2	1	0	NU
26.	Doing things with family relatives .....	3	2	1	0	NU
27.	Becoming more self-reliant and independent .	3	2	1	0	NU
28.	Telling myself that I have many things to be thankful for .....	3	2	1	0	NU

		(Circle number)				
		<i>Extremely helpful</i>	<i>Moderately helpful</i>	<i>Minimally helpful</i>	<i>Not helpful</i>	<i>Not used at all</i>
<b>COPING BEHAVIORS</b>						
29.	Concentrating on hobbies (art, music, jogging, etc.) .....	3	2	1	0	NU
30.	Explaining our family situation to friends and neighbors so that they will understand us	3	2	1	0	NU
31.	Encouraging child with cancer to be more independent .....	3	2	1	0	NU
32.	Keeping myself in shape and well groomed ...	3	2	1	0	NU
33.	Involvement in social activities (parties, etc.) with friends .....	3	2	1	0	NU
34.	Going out with my spouse or partner on a regular basis .....	3	2	1	0	NU
35.	Being sure prescribed medical treatments for child are carried out at home on a daily basis .....	3	2	1	0	NU
36.	Building a closer relationship with my spouse	3	2	1	0	NU
37.	Allowing myself to get angry .....	3	2	1	0	NU
38.	Investing myself in my child(ren) .....	3	2	1	0	NU
39.	Talking to someone (not professional counselor/doctor) about how I feel .....	3	2	1	0	NU
40.	Reading more about the medical problem which concerns me .....	3	2	1	0	NU
41.	Talking over personal concerns and feelings with spouse (or partner) .....	3	2	1	0	NU
42.	Being able to get away from home care tasks and responsibilities for some relief .....	3	2	1	0	NU
43.	Taking my child to clinic on regular basis .	3	2	1	0	NU
44.	Believing that things will always work out .	3	2	1	0	NU
45.	Doing things with my children .....	3	2	1	0	NU

## PART B

Another aspect of coping with childhood cancer involves family relationships. In this section, we would like to know which of the statements below are true of your family and which are false. If you think the statement is TRUE or mostly TRUE of your family, CIRCLE T (true). If you think the statement is FALSE or mostly FALSE of your family, CIRCLE F (false).

Please give us your general impression of your family for each statement. There are no right or wrong answers.

(Circle letter)

- T F 1. Family members really help and support one another.
- T F 2. Family members often keep their feelings to themselves.
- T F 3. We fight a lot in our family.
- T F 4. Activities in our family are pretty carefully planned.
- T F 5. Family members are rarely ordered around.
- T F 6. We often seem to be killing time at home.
- T F 7. We say anything we want to around home.
- T F 8. Family members rarely become openly angry.
- T F 9. We are generally very neat and orderly.
- T F 10. There are very few rules to follow in our family.
- T F 11. We put a lot of energy into what we do at home.
- T F 12. It's hard to "blow off steam" at home without upsetting somebody.
- T F 13. Family members sometimes get so angry they throw things.
- T F 14. It's often hard to find things when you need them in our household.
- T F 15. There is one family member who makes most of the decisions.
- T F 16. There is a feeling of togetherness in our family.
- T F 17. We tell each other about our personal problems.
- T F 18. Family members hardly ever lose their tempers.
- T F 19. Being on time is very important in our family.
- T F 20. There are set ways of doing things at home.
- T F 21. We rarely volunteer when something has to be done at home.
- T F 22. If we feel like doing something on the spur of the moment we often just pick up and go.

(Circle letter)

- T F 23. Family members often criticize each other.
- T F 24. People change their minds often in our family.
- T F 25. There is a strong emphasis on following rules in our family.
- T F 26. Family members really back each other up.
- T F 27. Someone usually gets upset if you complain in our family.
- T F 28. Family members sometimes hit each other.
- T F 29. Family members make sure their rooms are neat.
- T F 30. Everyone has an equal say in family decisions.
- T F 31. There is very little group spirit in our family.
- T F 32. Money and paying bills is openly talked about in our family.
- T F 33. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.
- T F 34. Each person's duties are clearly defined in our family.
- T F 35. We can do whatever we want to in our family.
- T F 36. We really get along well with each other.
- T F 37. We are usually careful about what we say to each other.
- T F 38. Family members often try to one-up or out-do each other.
- T F 39. Money is not handled very carefully in our family.
- T F 40. Rules are pretty inflexible in our household.
- T F 41. There is plenty of time and attention for everyone in our family.
- T F 42. There are a lot of spontaneous discussions in our family.
- T F 43. In our family, we believe you don't ever get anywhere by raising your voice.
- T F 44. Dishes are usually done immediately after eating.
- T F 45. You can't get away with much in our family.

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## PART C

Next, we are interested in how you feel your family has adapted to the experience of childhood cancer. Please read each item below and record HOW WELL YOUR FAMILY HAS ADAPTED in that specific category by CIRCLING THE NUMBER that best describes your own experience. The choices are:

- 1 = Worse than before (WB)
- 2 = Somewhat worse than before (BWB)
- 3 = Same as before (SAB)
- 4 = Somewhat better than before (BBB)
- 5 = Better than before (BB)

SINCE MY CHILD'S DIAGNOSIS, I HAVE BEEN ABLE TO:	(Circle number)				
	WB	BWB	SAB	BBB	BB
1. Keep up with household chores	1	2	3	4	5
2. Have enough money to cover expenses	1	2	3	4	5
3. Perform my work responsibilities	1	2	3	4	5
4. Do things with my family together	1	2	3	4	5
5. Enjoy my family's company	1	2	3	4	5
6. Engage in leisure-time interests and activities	1	2	3	4	5
7. Spend time with friends	1	2	3	4	5
8. Stay in touch with relatives	1	2	3	4	5
9. Take care of my own health	1	2	3	4	5
10. Attend church or synagogue	1	2	3	4	5
11. Express my feelings around other family members	1	2	3	4	5
12. Feel satisfied with my marriage	1	2	3	4	5
13. Discipline my children	1	2	3	4	5
14. Plan for the future	1	2	3	4	5
15. Meet the emotional needs of my child with cancer	1	2	3	4	5
16. Meet the emotional needs of my other child(ren)	1	2	3	4	5
17. Meet the emotional needs of my spouse/partner	1	2	3	4	5
18. Meet my own emotional needs	1	2	3	4	5
19. Meet the medical needs of my child with cancer	1	2	3	4	5
20. Maintain the overall quality of my family life	1	2	3	4	5

## PART D

Finally, we would like to ask you some questions about yourself for statistical purposes.

1. What is your gender? (Circle number of your answer)
  - 1 MALE
  - 2 FEMALE
2. What is your present age? \_\_\_\_\_ YEARS
3. What is your current employment status? (Circle number)
  - 1 NOT EMPLOYED
  - 2 EMPLOYED PART-TIME
  - 3 EMPLOYED FULL-TIME
  - 4 RETIRED
  - 5 FULL-TIME HOMEMAKER
4. What is your principal occupation? (Circle number)
  - 1 PROFESSIONAL  
(e.g., accountant, physician, registered nurse, manager, teacher, engineer, commissioned officer)
  - 2 SKILLED WORKER  
(e.g., police officer, sales, beautician, clerical, mechanic, foreman, licensed practical nurse)
  - 3 SEMISKILLED WORKER  
(e.g., laborer, hospital aide, assembly line worker, domestic)
  - 4 NOT EMPLOYED OUTSIDE THE HOME
5. How much school have you completed? (Circle number)
  - 1 NO FORMAL EDUCATION
  - 2 LESS THAN HIGH SCHOOL
  - 3 FINISHED HIGH SCHOOL
  - 4 COMPLETED SOME COLLEGE
  - 5 FINISHED COLLEGE
  - 6 ATTENDED OR COMPLETED GRADUATE SCHOOL
6. What is your religious preference? (Circle number)
  - 1 PROTESTANT
  - 2 JEWISH
  - 3 CATHOLIC
  - 4 OTHER (Specify) \_\_\_\_\_
  - 5 NONE

7. How would you describe yourself? (Circle number)

- 1 CAUCASIAN
- 2 BLACK
- 3 ASIAN
- 4 SPANISH-AMERICAN
- 5 AMERICAN INDIAN/INDIAN
- 6 OTHER (Specify) \_\_\_\_\_

8. What is your family's annual income? (Circle number)

- 1 UNDER \$5,000
- 2 \$5,000 - \$15,000
- 3 \$15,001 - \$25,000
- 4 \$25,001 - \$35,000
- 5 \$35,001 - \$45,000
- 6 OVER \$45,000

9. How would you describe your current financial situation?  
(Circle number)

- 1 NO FINANCIAL PROBLEMS
- 2 MODERATE PROBLEMS BUT MANAGING
- 3 SEVERE PROBLEMS AND STRUGGLING

10. What is your current marital status? (Circle number and  
fill in years)

- 1 NEVER MARRIED
- 2 MARRIED \_\_\_\_\_ YEARS
- 3 DIVORCED \_\_\_\_\_ YEARS
- 4 SEPARATED \_\_\_\_\_ YEARS
- 5 WIDOWED \_\_\_\_\_ YEARS

11. How many children do you have in each age group?  
(If none, write "0")

Number of Children

- \_\_\_\_\_ UNDER 5 YEARS
- \_\_\_\_\_ 5 - 13
- \_\_\_\_\_ 14 - 18
- \_\_\_\_\_ 19 - 24
- \_\_\_\_\_ 25 AND OVER

12. What is your relationship to the child with cancer? (Circle number)

- 1 MOTHER
- 2 FATHER
- 3 OTHER (Specify) \_\_\_\_\_

13. What is the sex of the child with cancer? (Circle number)

- 1 MALE
- 2 FEMALE

14. What type of cancer does the child have? (Circle number)

- 1 LEUKEMIA
- 2 BRAIN TUMOR
- 3 LYMPHOMA
- 4 NEUROBLASTOMA
- 5 WILM'S TUMOR (KIDNEY)
- 6 SOFT TISSUE (MUSCLE)
- 7 BONE TUMOR
- 8 OTHER (Specify) \_\_\_\_\_

15. What is the age of the child with cancer? \_\_\_\_\_ YEARS

16. How old was the child at time of diagnosis? \_\_\_\_\_ YEARS

17. How long ago was the child's cancer first diagnosed?  
(Circle number)

- 1 UNDER 3 MONTHS
- 2 3 - 6 MONTHS
- 3 7 - 11 MONTHS
- 4 1 - 2 YEARS
- 5 2 YEARS 1 MONTH - 3 YEARS
- 6 OVER 3 YEARS

18. Is the child currently in remission? (Circle number)

- 1 YES
- 2 NO

19. Has the child ever had a relapse or recurrence of the disease? (Circle number)

- 1 YES, \_\_\_\_\_ TIME(S)
- 2 NO

Is there anything else you would like to tell us about your coping experiences with childhood cancer? If so, please use the space below for your comments.

Thank you for completing this questionnaire! If you would like a summary of the results, please print your name and address on the back of the RETURN ENVELOPE (NOT on this questionnaire). We will see that you receive one.

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