

THOUGHTS, FEELINGS, AND ACTIONS: A RETROSPECTIVE
STUDY OF THE COPING EFFORTS OF PEDIATRIC CANCER
PATIENTS IN THE CONTEXT OF THE HOME,
INSTITUTION, AND COMMUNITY

by

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FAMILY AND CHILD DEVELOPMENT

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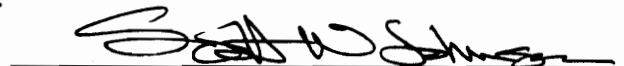


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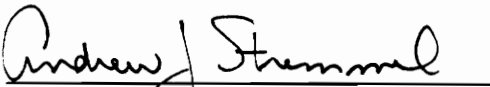
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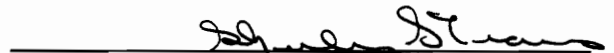
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ABSTRACT

This study was a retrospective examination of the experiences of pediatric cancer patients and their families from a contextual perspective. The home, institution, and community contexts were investigated to reveal their influences on the coping efforts of the study participants. Ten families of children with cancer were interviewed, and data were analyzed qualitatively. Walker's (1985) family stress model and Lazarus' (1984) coping paradigm guided the study.

The findings indicated that children were ambivalent in their attitudes toward the disease process. While they did not enjoy painful procedures, sickness, frequent hospitalizations, and baldness, they did welcome the special attention brought about by these stressors. Many of the children in the study understood the impact of their illness on the family. They felt guilty about family financial pressures, parental marital problems, and sibling conflicts that resulted from their cancer. Most feared relapse and death but hid their feelings to protect their parents.

Mothers handled the stress of their child's illness by learning all they could about the disease, focusing completely on the sick child, and protecting the child from further harm. Fathers tended to take on the role of "strong one" while worrying about finances and attempting to keep the families together. Differing ways of coping between mothers and fathers often caused feelings of resentment and marital difficulties. Parental

attitudes toward the staff at the medical center varied from trust, to wariness, to dependency. Parents enjoyed the support of family, friends, and community during the diagnosis phase, but felt bitter about the lack of support they received during the treatment and completion stages. Some parents believed that their exposure to the stressors of the illness process led to personal growth that they would not have experienced otherwise. Many parents emerged from the cancer ordeal with a desire to help others who were battling childhood cancer. They became involved in a variety of community agencies that served the families of children with cancer.

Dedicated to Daddy
who fights his daily battle with cancer
with dignity, courage, and faith.

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TABLE OF CONTENTS

ABSTRACT	iii
ACKNOWLEDGMENTS	v
I. INTRODUCTION	1
Statement of the Problem	1
Purpose of the Study	4
Research Questions	5
II. LITERATURE REVIEW	7
Conceptual Framework	7
Stress as Contextual	7
Lazarus Model	9
Review of Literature	14
Children's Perceptions of Health and Illness	14
Coping with Cancer and its Ramifications	17
Contexts in Which Children Cope	21
Summary	25
III. METHODOLOGY	26
Overview	26
Description of the Sample	29
Procedures	35
Analysis of Data	39

IV. RESULTS	42
Reactions and Interactions	43
Pain/ Sickness	75
Hospitalization	83
Baldness	89
Fear of Death	95
Actual Death and Keeping the Memory Alive	107
V. DISCUSSION AND CONCLUSIONS	113
Overview	113
Discussion of Findings	114
Theoretical Integration	114
The Illness Process	120
Coping with Specific Stressors	123
Contextual Layers	124
Limitations of the Study	127
Suggestions for Further Research	128
Summary	130
REFERENCES	132
LIST OF TABLES	
Table 1	32
Table 2	101
APPENDICES	
A: Interview Guides	136
B: Consent Form	146
C: Coding Scheme	148
D: Vita	154

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CHAPTER ONE

INTRODUCTION

Statement of the Problem

A young child peeks from behind the louvered doors of a linen closet, hoping to postpone his chemotherapy for a few more minutes. Two little girls without hair giggle and talk in the clinic waiting room as they await their weekly examinations. Upstairs, a thin and pale young boy sits alone in his hospital room, with all his favorite toys and possessions tucked around him in his bed, as if he is expecting to leave soon on a very long journey. Another child races down the hospital hallway in a wheelchair, laughing and shouting, as his friend pushes him and lifts the front wheels of the chair off the floor.

These children share the misfortune of having pediatric cancer. They have suffered innumerable hospitalizations, painful treatments, weakness, sickness, and dangerous side effects of drugs. They have looked death in the eye, they have known pain and suffering, and loss of dignity. Yet they have learned to cope in their own ways, and they have not forgotten how to laugh and play.

How do they maintain such resilience? How do they find the strength of character to cope with such stressors, in spite of their limited experience with life? How much do they understand about what is happening to them and their families? This study was designed to answer these questions. I interviewed 9 pediatric cancer patients, their families, and the representatives of the institution and community agencies that served them. This dissertation is the story of their experiences.

Pediatric cancer patients endure high levels of stress everyday as they encounter all that modern medicine has to offer (Saylor, Pallmeyer, Finch, Eason, Treiber, & Folger, 1987; Youssef, 1981; Zurlinden, 1985). Hospitalization is a major stressor for children (Rutter, 1981). Repeated hospitalizations during childhood have been shown to contribute to the development of psychiatric problems later in life (Zurlinden, 1985). Adult assistance is necessary to help children successfully handle the stresses of hospitalization (Rutter, 1981).

In the hospital, children are robbed of control as the option of escaping painful and anxiety producing procedures does not exist, and young patients are often separated from family, friends, and normal daily routines (Youssef, 1981). Saylor et al. (1987) found that the best predictor of emotional distress in hospitalized children was the number of physical stressors they endured, including confinement to bed, inability to toilet independently, injections, intravenous insertion, venipuncture, and various diagnostic procedures.

Pediatric cancer patients suffer multiple physical stressors. Their treatment includes such physical stressors as frequent venipunctures to assess the levels of cancer cells in the circulation, lumbar punctures to check the spinal fluid for the presence of the disease, and excruciating bone marrow aspirations in which a large needle is inserted into the hip bone to retrieve a sample of marrow. Furthermore, the medications used to force the cancer into remission are known to cause unpleasant side effects including nausea, vomiting, baldness and the death of many healthy cells, placing the child at risk for infections and further hospitalizations. Most children are not equipped to handle stressors of this magnitude. Adults in the child's environment must offer support as the child attempts to cope. How children cope with the stressors of chronic illness, how the adults in their lives are affected by the illness, and what they do to help the children cope were explored in this study.

Little is known about how children understand what is happening to them while these stressors are occurring. Children with cancer tend to keep their thoughts and feelings to themselves (Goggin, Lansky, & Hassanein, 1976). Bluebond-Langner (1978) found that children tended to talk to each other about what they knew or wanted to know about cancer, rather than discussing their disease related questions and perceptions with adults. Children perceived that adults would either become distressed about discussing cancer with the children, or they would "sugar coat" the painful issues. This study reveals what children think about their cancer, how they feel about

treatment, and how they cope with the implications of the disease. The children who were part of the research were asked to communicate this information by helping to write a book for other children with cancer.

In order to gain a clear understanding about what it is like to be young and suffering from a chronic, life threatening disease such as cancer, a contextual framework was necessary. I centered the investigation around the thoughts and actions of the children who suffer with cancer, but a complete picture could not be constructed without also gaining the perspectives of the children's parents, the institution that delivered their medical care, and the community agencies that offered support to them and their families.

Purpose of the Study

Several studies have been published recently that examine the experiences of children with cancer and other chronic illnesses, but none have utilized a contextual framework. In order to understand the thoughts, feelings, and actions of children with cancer, it is necessary to understand that children do not live in isolation from others. They are profoundly influenced by the adults in their lives, the institutions that deliver their medical care, and the community agencies that offer support. The purpose of this study was to investigate, from a contextual perspective, the experiences of children with cancer. More specifically, I sought to understand how the children perceived their

illness and how they coped with the multiple stressors they encountered during the diagnosis and treatment of the disease.

Research Questions

The following questions guided the research:

- 1) What are the children's thoughts and feelings regarding their illness?
- 2) How do the children cope with ramifications of the illness such as nausea, painful procedures, baldness, and uncertain prognosis?
- 3) What are the home, institution, and community contexts that surround the child during the coping process?

A qualitative perspective guided this study, yielding descriptive data about children's thoughts, feelings, and actions as they dealt with cancer and its ramifications. The particular methods used were interviews and projective story telling. Interviews were conducted with the children, their parents, members of the health care team at the institution that delivered their care, and representatives of community agencies that offered support to the children and their families. The interviews with the children utilized a different format than the parent interviews since young children rarely respond well to direct questioning about their thoughts and feelings (Ross & Ross, 1984). The children were asked to assist me in writing a book about a child with cancer. By doing so, they projected their own ideas about what cancer is, what causes it, how it is treated, and how to deal with the implications of the treatment, to the character of the book.

This approach was designed to obtain more candor and depth of response from the children than a structured interview process would have allowed.

Research was conducted with elementary school age children because they were old enough to verbalize their thoughts and feelings, but not old enough to have the more adult-like perceptions and coping skills typical of adolescents (Ross & Ross, 1984).

Children and their parents were interviewed in their homes. A snow ball technique was used to obtain names of families and children. Community agency representatives were recruited for interviews from the Candlelighter's Support Group, the American Cancer Society, and Camp Fantastic.

CHAPTER TWO

LITERATURE REVIEW

In this chapter the two theoretical frameworks will be discussed as they relate to the study, followed by a review of pertinent research from the literature. Both the Walker (1985) and Lazarus (1984) models guided the research. The Walker (1985) paradigm enlightened the investigation of family stress and coping. The Lazarus (1984) model assisted the exploration of individual coping efforts.

The review of literature will be presented under sub-headings that correspond with the research questions. First, literature about children's perceptions of illness will be reviewed, followed by research pertinent to the ways children handle the stressors specific to the diagnosis and treatment of cancer, and finally, literature about contextual layers. The material presented here will set the stage for telling the children's stories.

Conceptual Framework

Stress as Contextual

Walker's (1985) contextual model served as the primary framework for this study. Walker (1985) developed a family stress paradigm as an alternative to Hill's (1949) ABCX family crisis model. She argued that stress could not be properly investigated or understood by looking at one crisis event and the family's response to it. Instead, the "multiple interdependent levels of the social system" (Walker, 1985, p. 827) must be examined. The stressor and the individual's response to it are not discreet

events that can be labeled or predicted. Instead, the stressor and response have a ripple effect throughout the family and the social system so that each individual is affected differently and reacts differently.

Furthermore, family response cannot be perceived as one entity. The family is comprised of several different personalities and coping styles. The coping efforts of some individuals may actually potentiate the stress of others within the social structure. For example, the child with cancer may cope with the multiple stressors she encounters by becoming dependent and clingy. The mother, on the other hand, may feel the need to get away in order to cope with the situation. She might feel guilty about her desire for time alone because of the child's apparent need for her continual presence. Consequently, the mother may stay with the child but resent the imposition on her need to get away, thereby increasing her levels of stress because she feels guilty for resenting the child who needs her.

The circular nature of stress within the family and social system cannot be fully understood without research that is guided by a contextual framework. Individual perspectives regarding the stressful situation, the coping strategies preferred by each person within the social structure, and the interrelationship between the thoughts, feelings, and actions of each individual must all be considered (Walker, 1985). Family and individual resources also have a profound effect on coping efforts.

Walker (1985) emphasized that a qualitative approach is necessary for a full understanding of stress and coping. Family history, current family stage, and expectations for the future are all important factors for placing the crisis in context. Stressor induced actions and changes over time in the multiple levels of the social system must be the focus of the investigation, recognizing that the stressors can "both encourage and hinder individual, dyadic, and familial development" (Walker, 1985, p. 834).

In this study, the social levels of individual, family, institution, and community and their interrelations were investigated. An understanding of the child's perspective as well as the changes and reciprocal actions within the family as a result of the child's cancer were sought. Institutional policies and practices and the support offered by community agencies were expected to affect the family's coping efforts and their ability to support the child as she experienced the disease.

Walker's (1985) contextual model served as the primary conceptual framework for this study. Lazarus' (Lazarus & Folkman, 1984) coping paradigm was utilized to evaluate the individual thoughts, feelings, and actions of the children and family members.

The Lazarus Model

The Lazarus (1984) model of stress and coping guided the exploration of individual stress and coping in this study. Lazarus (1984) defined stress as "a particular

relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus, 1984, p. 19). Coping was defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus, 1984, p. 141).

Lazarus (1984) viewed coping as a transactional process between the person and the environment involving the person's thoughts, feelings, and actions. He saw the process as dynamic, mutually reciprocal, and bidirectional. Events are constantly unfolding and changing as the person and the environment change. Lazarus (1984) and Walker (1985) both advocated that coping cannot be adequately evaluated without taking into consideration the context in which it occurs, including the person's history, stage of life, and the overall present circumstances.

Lazarus (1984) proposed that an individual's response to stress must be evaluated on three different levels: 1) the social level, which deals with interactions with others, 2) the psychological level, which is comprised of individual thoughts and actions, and 3) the physiological level which is made up primarily of the emotions. The degree of threat a person experiences for any given stressor is determined by the person's commitments, vulnerabilities, beliefs, and resources. Consequently, each individual encountering a stressor will appraise it differently and therefore react differently.

Cognitive appraisal is the basis for all coping efforts, according to the Lazarus (1984) model. A primary appraisal is made to evaluate whether the event is potentially harmful, potentially beneficial, or irrelevant. Secondary appraisal involves mentally scanning the coping alternatives available, and reflecting on their potential for effectiveness. Reappraisal is often necessary as original perceptions change in light of new information, changing internal or external conditions, and/or feedback.

Coping efforts are divided into two categories: those that are problem focused and those that are emotion focused. Emotion focused coping would include trying to forget an incident, taking a positive outlook, or accepting support from others. Problem focused coping would include talking things out with someone to get them to change their mind, making a plan of action and then following it, or fighting to get something changed. Sometimes the distinctions between the two are blurred or non-existent. In addition to the two categories of coping proposed by Lazarus (1984), coping efforts are further broken down into four basic modes: 1) direct action, 2) inhibition of action, 3) information seeking, and 4) intrapsychic.

Like Walker (1985), Lazarus (1984) stressed the qualitative approach for assessing the process of coping over time. He emphasized that information must be gained about the person and his/her responses along with the social context that surrounds the stressful event.

Lazarus (1984) recommended the self-report approach to stress and coping research. He emphasized that the self-report must "1) refer to specific thoughts, feelings, and acts rather than what a person reports he or she might or would do; 2) be examined in a specific context; and 3) be studied in slices of time so that changes can be observed in what is thought, felt, and done as requirements and appraisals of the encounter change" (Lazarus, 1984, p. 317).

Lazarus (1984) acknowledged the criticisms leveled at self-report techniques, particularly the inaccuracies of memory, the desire of the subject to appear socially acceptable in the researcher's eyes, and the difficulty of identifying exact thoughts and actions connected with specific stressful encounters. However, he still advocated self-reporting as a valuable research tool. According to Lazarus (1984), if self-report measures were eliminated, further research on thoughts, feelings, and emotions would be impossible.

Application of Lazarus Model to Children's Coping

Although the Lazarus (1984) model is primarily an adult model of stress and coping, it has been used to guide numerous research studies that investigated children's response to stress (Caty, Ellerton, & Ritchie, 1984; Caty, Ritchie, & Ellerton, 1989; Ellerton, Ritchie, & Caty, 1989; Hamner & Miles, 1988; Ritchie, Caty, & Ellerton, 1984; Ritchie, Caty, & Ellerton, 1988; Scavnicky-Mylant, 1987; Wertlieb, Weigel, & Feldstein, 1987).

Caty, Ritchie, and Ellerton, modified Lazarus' (1984) model to fit children by collapsing the 4 coping modes into 3 major categories and 11 subcategories. The three major categories were 1) Information-Exchange, 2) Action-Inaction, and 3) Intrapsychic.

The Information-Exchange dimensions included the child's attempts to gain information by listening, asking questions, and watching; as well as information limiting behaviors such as changing the subject, and information giving behaviors like communicating information and explaining self to others. The Action-Inaction dimension was made up of 8 subcategories including behaviors that were mastering, controlling, tension reducing, self-protecting, self-comforting, and behaviors that solicited help from others, expressed emotion, or indicated a decision to move to a higher level of independence. Intrapsychic behaviors included defense mechanisms and mental processes to regulate emotion (Caty et al, 1984).

In this study, it was expected that the coping strategies children used would have changed as their disease progressed because of the processual nature of the coping response. Furthermore, coping efforts were predicted to be highly individualized and greatly dependent on the social context in which the children lived. Parental beliefs and values were expected to have an important influence on the children's coping behaviors as well as the level of threat inherent in the type of treatment the children received.

In summary, two conceptual models were utilized to guide this investigation. The Walker (1985) paradigm served as the primary conceptual framework for this study and Lazarus' (1984) model guided exploration of individual thoughts, feelings, and actions identified in the research data.

Review of Literature

In the review of literature, studies related to each of the research question will be presented separately. First, studies related to children's understanding of health and illness will be discussed. Next, literature about children's coping will be reviewed. Finally, studies that described the contexts in which children cope will be presented.

Children's Perceptions of Health and Illness

As children grow older they progress in their understanding of illness, contagion, and the origin of disease (Bibace & Walsh, 1980; Kister & Patterson, 1980; Perrin & Gerrity, 1981). With respect to contagion, younger children are often apt to over-extend the concept to include non-transmissible ailments as well as accidents. Most children understand that proximity to the sick person increases the well person's risk for "catching" the illness.

Sixty per cent of the children in Kister and Patterson's study (1980) attributed sickness to immanent justice. Believing in immanent justice was highly correlated with misunderstanding contagion. Children who did not understand the transmission of

diseases from one person to another tended to manufacture their own explanations, and wrong doing on the part of the sick child seemed logical to them.

Perrin and Gerrity (1981) investigated children's responses to questions about the physical world as well as illness. Children tended to be much more knowledgeable about the world around them than about illness. The researchers concluded that children were more familiar with the physical world because they had had more exposure to it. They recommended further research to investigate understanding of disease among ill children.

Campbell (1975) interviewed children who were hospitalized for short term medical problems. The maturing affect on a child's understanding of health and illness was only noted when the child's experience with health problems occurred at a later age. Children who encountered significant health problems at a young age were actually less developed in their understanding of illness than healthy children. The trauma of medical problems early in life caused regression in maturity rather than increased sophistication of knowledge.

Campbell's (1975) research could have been strengthened if he had included in his sample, a group of children who were chronically ill. Comparisons could have been made between the perceptions of the chronically ill children and the children who were hospitalized for short term illnesses.

Chronically ill children do exhibit a clearer understanding of death than other children their age. Pediatric leukemia patients were compared with healthy children in regard to their understanding about death (Clunies-Ross & Lansdown, 1988). Leukemic children were more likely to understand the concepts "cessation of bodily functions" and the "irrevocability of death" than the well children.

When the same children were asked to draw pictures of themselves in the hospital, drawings revealed a sense of isolation. Children tended to draw themselves alone in the hospital, with sad or crying faces. In reality, the children were seldom alone in their hospital rooms. Parents, play therapists, or nurses were with the children almost constantly.

The findings of Clunies-Ross and Lansdown (1988) offer insight into the perceptions of children who are chronically ill, but they cannot be assumed to apply to all sick children because of the relatively small sample size and the fact that no triangulation of method was attempted. Observation of the children in the hospital in addition to the interviews, would have strengthened the study. Also, although leukemic children in the study were asked about illness and death, they were not questioned specifically about their understanding of their own disease and its implications. In the present study, chronically ill children were asked to reflect upon the origins and implications of their own illness and triangulation of both method and data sources was employed.

Coping with Cancer and Its Ramifications

Relatively little has been written in recent years about children's ability to cope with the stressors inherent to the diagnosis and treatment of childhood cancer. Of the studies that have been conducted, few focus on the thoughts, feelings, and actions of the children, as advocated by Lazarus (1984), and none utilize a contextual framework. In this review of children's coping literature, preference will be given to studies that utilized self-report techniques and were based on the Lazarus (1984) model of stress and coping.

Children's ability to talk about stress and coping. One hundred and seventy six children interviewed about their coping efforts in non-medical situations were quite capable of talking about stressful events in their lives and describing the coping behaviors they had utilized in dealing with non-medical situations (Wertlieb, Weigel, & Feldstein, 1987). Pediatric leukemia patients as young as 4 years old interviewed before and after a painful diagnostic examination detailed the coping strategies they had used during the procedure. They also rated the coping efforts according to which were the most and least helpful (Hamner & Miles, 1988).

Children's ability to make accurate threat appraisals. Lazarus (1984) argues that cognitive appraisal is the basis for all coping. Scavnicky-Mylant (1987) investigated the ability of children to make accurate threat appraisals. She postulated that accurate threat appraisals require "fairly mature development of ego, language, cognition, and general psychological structure" (Scavnicky-Mylant, 1987, p. 504), qualities that young

children often lack. Threat appraisal also includes a person's ability to scan available coping options and decide which ones will work effectively without causing further harm. Children's lack of experience with the world could cause them to make poor judgments. For example, they may not understand that relief of pain is sometimes brought about only by painful interventions. They may fail to utilize available resources such as pain medications because of their fear of injections.

Scavnicky-Mylant (1987) evaluated 30 children's appraisal of threat by asking them to talk about pictures of children in the hospital environment. Younger children tended to react negatively to all the pictures including the situations that held no potential for pain or injury. Older children were better able to distinguish between situations of threat and situations that were non-threatening, such as temperature taking and x-rays.

Children's ability to cope with pain. Children with leukemia were interviewed prior to bone marrow aspirations, observed during the procedure, and then interviewed again afterwards to evaluate the effectiveness of their coping efforts (Hamner & Miles, 1988). The children reported that the most stressful aspects of the bone marrow aspiration were the pain during the procedure, and the anticipatory anxiety before it began. The coping behaviors they used were primarily aimed at tension reduction and comforting self.

In the post procedure interviews all of the children expressed that the presence of a parent during the ordeal was most helpful. This fact emphasizes the importance of adult support in the lives of pediatric cancer patients.

Hamner and Miles' (1988) study could have provided further insights into the coping skills of the children if a more contextual approach had been used. Parents and medical staff could have provided additional information about the child's coping efforts.

The importance of parental presence was borne out in other studies as well (Siegal & Smith, 1989; Shaw & Routh, 1982). Five year olds observed during visits to the pediatrician's office showed that although children exhibited more signs of distress when the parents were present, the emotional turmoil resulting from procedures was shortened when parents were allowed to stay with the children (Shaw & Routh, 1982).

Children's ability to cope with hospitalization. Play interviews conducted with hospitalized children demonstrated that chronically ill children showed much more frustration in their play than the other children (Ritchie, Caty, & Ellerton, 1988). The researchers then conducted a study to compare the coping skills of acutely and chronically ill children.

Hospitalized children with acute and chronic illnesses were observed during periods of high and low stress to examine their coping behaviors (Ritchie et al, 1988). Children hospitalized with acute conditions exhibited more coping behaviors during low

stress events than high stress events. They were so overwhelmed by high stress events that they were unable to cope.

Chronically ill children, however, were able to cope with high stress events by asking for assistance from others in the environment, supporting Lazarus' (1984) argument that coping skills evolve as the person learns to deal with a certain stressor. The coping strategies of the chronically ill children were more highly developed than the children with acute conditions, because they had dealt with painful and intrusive procedures for a longer period of time.

Children's ability to cope with baldness. The issue of baldness in pediatric oncology patients was virtually ignored in the coping literature. Baldness is a side effect of many anti-cancer drugs, occurring at least once with almost every child treated for any type of malignancy.

Only one research article mentioned the problem of baldness in pediatric cancer patients. A study of the concerns of parents in a support group for families of children with cancer (Heffron, Bommelaere, & Masters, 1973) reported that baldness was as much of a stressor for the parents as it was for the children. Parents reported that they had more difficulty coping with their child's baldness than with painful procedures and the threat of death. The present study provides additional information about the ways children and their parents cope with baldness.

Contexts in Which Children Cope

Literature describing the context that surrounds children as they cope will now be reviewed. Children do not cope in isolation. The adults around them, including those in the home, institution, and community are all potential sources of support. Research concerning each contextual layer will be presented.

The family. The family serves as the major source of support for sick children. Brett and Davies (1988) explored family coping using Lazarus' (1984) model and discovered changes in parental threat appraisals during the illness process.

At the time of diagnosis parents were in a state of alarm. They believed that survival of their child was impossible. During the treatment phase parents tended to reappraise the situation and enter a state of vigilance in which they believed that survival of the child was possible but not probable. At the end of the treatment phase, parents realized that their child was doing well. They entered the relaxed vigilance stage in which they believed that their child would probably survive if health status was carefully monitored. Although Brett and Davies (1988) offered valuable insight into the perceptions of the family, they virtually ignored the sick child in their research.

Another study of parents and siblings of pediatric cancer patients focused on family roles and the expression of emotions (Koch, 1985). Families who encouraged emotional expression and flexible roles experienced greater family closeness as a result of their child's illness. However, families who prohibited emotional expression and

maintained rigid roles were more likely to suffer health and behavioral problems among parents and children.

Soccorsi, Lombardi, and Paglia (1987) found that families of pediatric cancer patients centered their coping efforts around trying to ward off the possibility of death. Families tended to lock into rigid behaviors that governed the expression of emotion and the discussion of the disease in hopes that they could "capture death" and prevent its occurrence. The sick children learned to deny knowledge of their disease to spare their parents the emotional burden of recognizing the possibility of death. Siblings took on the role of emotional orphans to allow the family to center their attentions on the sick child. After treatment was completed and the danger of death had passed, family members gradually began to talk with each other about their feelings and fears.

This review of studies demonstrates that the entire family experiences tremendous emotional upheaval as a result of the illness process. The guidance and assistance of others from outside the boundaries of the family is often warranted.

The institution. Medical center personnel have developed many ways of assisting chronically ill children in coping with the stress of hospitalization and painful treatments. Play sessions with medical equipment are useful in helping children master the stress of intrusive procedures (Ellerton et al., 1985). Children tend to act out, with great vengeance, the procedures they have experienced. Injections are portrayed as acts of violence as children stab dolls and stuffed animals in unusual injection sites such as

the eyes and abdomen. Play is useful for venting pent up frustrations in young hospitalized children.

Behavior management in the form of rewards, guided imagery, rehearsal, and film modeling have also been attempted (Jay et al., 1985). Children were promised trophies if they were able to lay still during painful procedures. All 5 children exhibited less distress during the procedure for which their control was rewarded. However, the findings of this study must be questioned because of the small sample size and the fact that internal physiological indicators of distress, such as pulse and blood pressure, were not monitored. The children may have inhibited their outward distress behaviors in order to gain the trophy, while distress was raging inwardly.

A coping technique called thought stopping, was developed by Ross (1984). She taught children to recite a set of memorized phrases to themselves each time they became anxious about an impending event. By repeating the memorized phrases as many times as necessary, the children were able to conquer anticipatory anxiety before procedures. Other techniques used to help children cope with hospital stressors included distraction, hypnosis (McCaul & Malott, 1984; Patterson & Ware, 1988; Suderman, 1990), giving children a sense of control (Hunsberger, Love & Byrne, 1984), and various pharmacological interventions (Suderman, 1990; Zeltzer, Jay, & Fisher, 1989).

In addition to helping the children cope, many institutions offer assistance to the family in the form of professional counseling from staff psychologists and family

therapists (Friedrich & Copeland, 1983). The stress of having a child with cancer exacerbates family conflicts already present before diagnosis. However, while dealing with cancer, families are unable to deal with behavior problems because they are overwhelmed with stress.

The community. Little in the formal literature details the contributions of community agencies in the support of pediatric cancer patients and their families. However, two studies were found. The first describes the focus and goals of the Candlelighter's Foundation, and the second reports the impact of summer camp on the children and their families.

The Candlelighter's Foundation is dedicated to meeting the educational and psychosocial needs of young cancer patients and their families (Nathanson & Monaco, 1984). Publications, audio-visual materials, and informative conferences are available as resources for parents and children. Local chapters of the Candlelighter Foundation initiate support groups to meet the emotional and social needs of families in the community.

Summer camps exclusively for children with cancer are also useful in meeting the needs of pediatric cancer patients and their families. Smith, Gotlieb, Gurwitch, and Blotcky (1987) conducted a longitudinal study to assess the affects of summer camp on daily activity and family interactions. Children who attended camp were more

independent and engaged in more physical and social activity one month after the camp experience.

Family interactions were different as a result of the camp experience in that mothers tended to spend more time with the siblings of the sick child and more social time with people outside the family one month after the child returned from camp. Changes were attributed to the fact that, at camp, pediatric cancer patients were encouraged to participate in a wide range of physical and social activities with other children who shared the same type of illness. As a result the mothers were able to temporarily overcome the tendency towards overprotectiveness, and the children were more self-confident about their physical and social skills (Smith et al. 1987).

Summary

In this chapter, research studies investigating children's understanding of illness, children's coping strategies, and contextual factors that surround sick children have been reviewed. Few of the studies reviewed here utilized self-reports of the thoughts, feelings, and actions of the children in relation to specific stressors. None of the studies examined contextual layers. The present study will add to the existing body of knowledge on children's coping, and explore new avenues as it explores how children with cancer feel about their own illness, how they cope with baldness, and the context that surrounds them as they cope with cancer.

CHAPTER THREE

METHODOLOGY

Overview

The purpose of this study was to examine, from a contextual framework, how children with cancer understand their illness, how they cope with the stressors inherent to the disease, and how the contextual layers that surround them contribute to their coping. A qualitative approach, advocated by both Walker (1985) and Lazarus (1984), was taken. Strauss and Corbin (1990) define qualitative research as "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification" (p. 17). They recommend this form of research when the purpose of the study is to "uncover the nature of a persons' experience with a phenomenon, like illness, religious conversion, or addiction" (p. 19), or when little is known about the topic under investigation.

The qualitative approach is useful when an understanding of the multidimensional character of the participants is desired. The in-depth interview approach allows the families to "tell their experiences in their own words and from their own perspectives" (Allen & Pickett, 1987, p. 518). Qualitative methods allow the researcher to focus on the actions and interactions between family members, with other families, and with outside systems (Gilgun, 1992).

Previous studies which investigated children's perceptions of illness have demonstrated that children are capable of accurately reporting their experiences (Elwood, 1987; Savedra, Tesler, Ward, Wegner, & Gibbons, 1981; Wilkie, Holzemer, Tesler, Ward, Paul, & Savedra, 1990). Hamner and Miles (1988) found that children as young as 4 were able to verbalize "specifically about the procedure and to tell the investigator what aspects of the procedure they found scary and what made them feel more comfortable" (p. 14).

The methodology for this study covered four levels of the social structure that make up the context in which children experience cancer; children, family, institution, and community. This research design was necessary for analyzing the interplay of stress and coping between "the multiple interdependent layers of the social system" (Walker, 1985, p. 827).

Interviews with children, their parents, representatives of the institution, and members of community agencies were conducted. Self-reports from children about their coping behaviors yielded data that could be labeled "meta-coping" since it revealed how the children viewed their own coping, but not necessarily how they actually coped (Wertlieb et al; 1987). Interviews with parents served as a form of triangulation of data to give information about how the children actually reacted during stressful times, thereby providing for greater validity and reliability. For this reason, the data will be supported with quotations from both parents and children.

Denzin (1989) defines triangulation as a combination of methods, data sources, theories, and/or investigators. In this study, the subject of children's coping was examined from many perspectives by using a variety of methods (interview and projective story telling), data sources (children, parents, institution and community representatives), and theories (Lazarus, 1984; Walker, 1985). Specific information about how data were gathered from each of the four levels of the social structure will now be discussed.

Nine children with cancer were interviewed individually in their homes using a projective story telling technique in which I asked them to help me write a book about cancer for newly diagnosed pediatric cancer patients. I placed the children in the role of expert and asked them to inform me about their experiences.

The parents of the 9 children and the mother of one child who had died of leukemia one year prior to the time the research was conducted, were interviewed in their homes. They were questioned about how the children thought, felt, and acted during their experiences with cancer, how the disease affected the family, and what parents did to assist their children in coping.

The nurse practitioner at the medical center was interviewed for her perspective on what the children thought about their disease, how they coped with the stressors they encountered while visiting the clinic, and what the medical team did to support the children and their families as they coped. To gain a community perspective,

representatives of the Candlelighter's Support Group, the American Cancer Society, and Camp Fantastic (a camp for children with cancer), were interviewed to gather information about how they supported the children and their families during their battle with cancer.

Description of the Sample

Sample Selection

The search for names of potential sample participants was initiated at the children's medical center. However, because of confidentiality constraints the institutional representative was unable to release names of children with cancer. I was advised to submit my research proposal to the University of Virginia Human Subjects Review Board. The proposal was rejected by the board, blocking access to necessary information. Internal changes occurring within the Pediatric Oncology Department were cited as reasons for the rejection. They did not wish to have outsiders conducting research in the department at that time. It was later revealed, during the course of data collection, that because of certain political difficulties within the institution, the entire medical staff had resigned, and the department was essentially closed.

The proposal was next presented to the monthly meeting of the Candlelighter's Support Group in Charlottesville in an effort to recruit families for the sample by including a synopsis of the research proposal in their June newsletter. From this list of potential families, a sample that represented a variety of childhood cancers, socio-

economic levels, and stage of disease was to have been formed. However, the newsletter never materialized because during that time the chairperson was emotionally overwhelmed by the first anniversary of her son's death.

As a result of these problems, it was necessary to form a sample by the snowball method (Denzin, 1989). I knew of one family whose daughter had recently finished treatment for leukemia. She and her family were interviewed and asked for the names of other families. They provided the names of two other families and each of those was also interviewed and asked for names. The process continued until the contacts were exhausted. Due to the method used for the selection of the sample, most of the families interviewed were in the same "cohort" of patients, and most of the children had completed treatment at the time of the interview. Consequently, the study became retrospective in nature. This proved valuable since each family was able to report about the entire process from diagnosis to completion.

Sample Participants

The sample consisted of 10 families who had children with cancer. Only children who were diagnosed with cancer between the ages of 4 and 8 were eligible. Of these children, 5 lived with two parents, 3 lived with a mother and a step-father, and 2 lived with mothers in single parent homes. In the families with two parents in the home, both parents were interviewed together. The only exception was Brad's family. His mother had remarried only months before the interview, and the step-father had not been a part

of the family during the diagnosis and treatment of Brad's cancer, so he was not interviewed.

The children in the sample were between the ages of 4 and 8 at the time of diagnosis and 8 and 11 at the time of interview. Of the 5 girls and 4 boys in the sample, all had completed treatment at the time of interview except for one boy who had relapsed and has since died. The tenth child had died one year prior to the time his family was interviewed. Therefore, although 10 families were interviewed, there were only 9 children in the sample.

A variety of cancers were represented among the children interviewed. Six children had leukemia, one had lymphoma (a malignant tumor) and leukemia, one had osteosarcoma (bone cancer), another had rhabdomyosarcoma (brain tumor), and the last had Wilm's tumor (a tumor of the kidney). Table 1 gives information about the age of the children when they were diagnosed with cancer, their age at the time of interview, the date they completed treatment, and how long they had been finished with treatment at the time of the interview.

Table 1. Age at Diagnosis and Interview and Time Off Treatment at Time of Interview

Name	Age at Diagnosis Interview	Age at Completion	Date Treatment Completed	Time Off Treatment
D. J.	6	8	12/90	8 months
Catie	5	10	2/90	1yr/4mo
Lisa	7	11	5/90	1yr/2mo
Renee	6	10	11/89	1yr/9mo
Andy	4	8	4/91	3 months
Molly	6	11	12/88	2yr/8mo
Camden	6	11	Relapsed	Ongoing
Brad	8	10	9/89	1yr/10mo
Brenda	5	9	6/90	1yr/2mo
Alex	5	Deceased	---	-----

Introduction of the Participants

D.J.: D.J was an 8 year old boy who had lost his right leg to cancer, but he functioned amazingly well on a prosthetic leg. He enjoyed riding a scooter and playing sports with the other children. He lived with his mother and father and had no siblings.

Catie: Catie was a 10 year old girl with leukemia. She had a very rare type of chromosome in her leukemic cells and will probably relapse at some point in the future. At the time of the interview, she was in remission and doing very well. She enjoyed caring for her pets and her baby sister. She lived with her mother, father, and three younger siblings.

Lisa: Lisa was an 11 year old girl with leukemia, however her disease was discovered in a routine check-up before she ever had any symptoms, so her illness was mild and easily treated. She enjoyed soccer and basketball. She lived with her mother and her two older brothers.

Renee: Renee was a 10 year girl who had both a lymphoma and leukemia. She was very ill and nearly died in the early stages of treatment. She had many pets and

enjoyed wearing wild wigs. She lived with her mother and her step-father. She had a brother who lived with his father but visited frequently.

Andy: Andy was an 8 year old boy with leukemia. He was in remission and doing well. He had only been off treatment for a couple of months at the time of interview. He was a very good nintendo player and enjoyed swimming in his backyard pool. He lived with his mother, father, and two younger siblings.

Molly: Molly was an 11 year old girl with rhabdomyosarcoma, which is a rare form of brain tumor. She was in remission but still suffering some effects of her illness. She enjoyed playing with her friends and she was home schooled by her mother. She lived with her mother, father, and three younger siblings.

Camden: Camden was an 11 year old boy with leukemia. He loved to build trucks and equipment with legos, and he was a very good artist. He died of his disease about three months after his interview. He lived with his mother, step-father, and twin sisters.

Brad: Brad was a 10 year old boy who had a Wilm's tumor, which is a malignant tumor of the kidney. He loved to skateboard and play baseball. He lived with his mother, step-father, and his younger sister.

Brenda: Brenda was a 9 year old girl with leukemia. She had a dog named "Chemo" and loved to go to camp. She lived with her mother, father, and three younger siblings.

Alex: Alex was a boy with leukemia who died about a year before his family was interviewed. However, his mother was able to tell me about how he handled his illness and his death. He loved to build lego cities and play with his G.I. Joe toys. He lived with his mother and had no siblings.

Nurse Practitioner: Nancy was the nurse practitioner at the children's medical center. She coordinated the children's care and made referrals to outside agencies for support. She also performed most of their tests, administered the chemotherapy, and taught the parents how to care for their children at home. She has since left the medical center and returned to school full-time.

Camp Director: David was the director of Special Love, Inc., an organization dedicated to meeting the needs of children with cancer and their families. He headed up

Camp Fantastic, Top Brass Camp, and 4 retreats yearly for the families of these special children.

Candlelighter's Support Group: Two women were interviewed about the services of this support group. One was the current president of the group and the other was a past president.

American Cancer Society: Brenda's mother was very involved in the cancer society as well as having a child with leukemia, so her interview served two purposes. She was able to tell me about having a child with cancer and about the services of the cancer society for families like her own.

The Researcher: I came to this research study with 8 years experience in pediatric nursing, and 18 years experience as a parent. I have a love for children with cancer borne of my research at the medical center while earning a master's degree in pediatric nursing. In addition, I have had the privilege of caring for a number of my study participants in the hospital in the years prior to the study. Catie was a child I met at the medical center through earlier research. Brad, Andy, and Camden had been my patients at the hospital where I "moonlight" on weekends. Brad had been admitted with complications of his chemotherapy, Andy had the chicken pox, and Camden had frequent admissions for sepsis. I also cared for Camden during the weeks preceding his death and included my observations of that time in this study.

Protection of Subjects

Children were placed in the sample only after permission was granted by both the parents and the child. All participants were assured of confidentiality and the right to terminate participation in the study at any time. The names used in this report of the research are fictitious to protect the identity of the children. The proposal for this study was approved by the Institutional Review Board at Virginia Tech and the five faculty members on my dissertation committee.

Procedures

As the names of the families were obtained, I contacted them by telephone and asked them to participate in the study. I told the parents about the separate parent and child interviews and briefly informed them about the type of information that I was seeking. If they agreed to participate, the interview was scheduled. None of the families contacted refused to participate.

One of the reasons the families were willing to share in their experiences was because I told them that I planned to use the information to write a book about cancer for children. I explained to them that I wanted to let their children be the experts in telling me about their cancer experiences. Most of the parents were glad to give their children an opportunity to play this role.

Also, each family was referred to me by another family. I was able to tell each new set of parents that they could contact the referring family if they had any questions about what the interviews involved or how the children responded. Because all of the participants expressed positive feelings about the interviews, new families were reassured about joining the study.

Parent Interviews

Upon my arrival at the home, the parents were asked to read and sign a consent form which assured confidentiality, summarized the purpose of the study, and granted permission to interview both the parents and the child. The parents were then

interviewed using the interview guide as an outline. The interview was tape recorded for later transcription. The parent interviews lasted approximately 2 hours, with a range from 1 1/2 hours to 3 hours.

Parents of three families chose to have the child present at the time of their interview even though I suggested during our telephone conversation that the parent interview take place in a room where parents could talk privately. The decision to include the child in the parent interview probably reflected the open communication styles of those families. They were reluctant to exclude the child from conversations about the illness. I noticed that in the families where children were excluded from parental interviews, the children could often be seen hiding nearby listening to what was being said.

Child Interviews

After parent interviews were completed, children were asked if they would help me write a book about a boy or girl with cancer. Before beginning the projective story telling, children were asked to verbally express their consent to participate, and it was tape recorded. The tape recording was then played back to the child under the guise of "checking to make sure the tape recorder was working" (Ross & Ross, 1984). Hearing their voices on tape seemed to boost the children's confidence and increase their willingness to participate.

Next, we proceeded with the projective story telling technique. Younger children were read the story verbatim (see Appendix A) and asked to fill in the empty parts. As they dictated, I wrote, word for word, what they said and asked questions for clarification of thoughts and feelings. The children were quite impressed that their words were taken so seriously and worked very hard to dictate a good story. The story line was summarized for the older children, and they were asked what should be written about each of the problems that the child in the book encountered.

All of the children were assured that they were the experts (Ross & Ross, 1984) and that they were the authors of the book. Each child was asked to sign the author's page and draw a picture to illustrate the book. Although the children were asked to talk about the experiences of Tommy or Susan, the characters in the book, they all seemed to realize that their own experiences were the real basis for the story. Each of them drew a self-portrait when asked to illustrate the book. One girl actually verbalized the realization. When asked to dictate an "end to the story", she replied, "Well, I really don't know, because my story isn't over yet."

At the conclusion of the interview, children were invited to keep the package of felt tip markers they had used to draw the picture, and they were assured that a copy of the book would be mailed to them when it was completed. A card was mailed to the children the day after their interviews, thanking them for participating and praising them for the good job they had done. Two of the children were so pleased with the

whole process that they invited the researcher to come and interview them again.

Another child, when questioned by her mother about the content of the interview, said, "I wrote a really good book."

Institution and Community Interviews

Representatives of the medical center and community agencies were interviewed in their homes or offices using the interview guide in Appendix A. These interviews were also tape recorded for later transcription. The nurse practitioner of the medical center's Pediatric Oncology Department served as the institutional representative. She was selected because her name was mentioned frequently by parents as the person who provided the "human contact and caring" at the medical center. Community representatives from Camp Fantastic, The American Cancer Society, and The Candlelighter's Support Group were also interviewed. I learned of the support group from the nurse practitioner when she referred me to them as a way of gaining participants for my study. I attended 1 of their meetings and interviewed the current president of the group and a woman who served in that capacity several years earlier.

I contacted the woman who was in charge of a parent retreat sponsored by the American Cancer Society when one of the parents gave me a pamphlet about the retreat. The mother was actively involved in the cancer society as well as having a daughter with leukemia who met the eligibility requirements for the study. Consequently, I

interviewed the family about their cancer experiences and interviewed the mother about the activities of the cancer society.

When the topic of summer camp was frequently mentioned in parent and child interviews, I decided that I needed to interview a representative of that community agency. I contacted "Special Love" and set up an interview with the director of the summer camping program for children with cancer called Camp Fantastic.

All the community agency representatives who were interviewed were familiar with the cohort of families in this study, because the families had been served by their agencies. The nurse practitioner was intimately familiar with each of the families, because she had coordinated their care from the time of diagnosis through completion.

Analysis of the Data

The suggestions of Taylor and Bogdan (1984) guided the intensive data analysis process. Initially, all the taped interviews were transcribed verbatim, and two copies were made. Each transcript was copied on a different color paper so that the origin of quotations could be easily identified later in the analysis process. I read the transcripts of the taped interviews several times in their entirety. Then, major themes were identified, and transcripts were coded and cut so that the quotations dealing with each theme were in separate piles for more in-depth analysis.

Piles were further separated into stacks of quotations by or about the children, statements made by the parents about their own coping efforts, and quotations from

institutional and community agency representatives. Each pile of quotations was then analyzed for concepts and sub-concepts pertinent to each theme, so that a picture of the interrelated stressors and coping strategies within the layers of the contextual system could be visualized.

For example, the first sorting of the quotations was according to the major themes: diagnosis, treatment, and completion, and the four contextual layers. In one pile were all the quotations about the children during the diagnosis period. Some were comments the children had made about themselves, and others were statements made by the parents about how the children acted and reacted during the diagnosis phase. Another pile was all the quotations about parental reactions to the diagnosis phase, and a third pile contained the quotations by institutional and community representatives about their observations and interventions during the diagnosis phase. Treatment and completion phases were sorted in the same manner.

Next, each of the piles was separated according to concepts that were derived from the research questions. For example, the pile of quotations about the children during the diagnosis phase was further divided into separate piles of quotations about how they reacted to the diagnosis itself, how much they understood about what was happening to them, and how they handled the painful treatments, hospitalization, and baldness. By sorting each of the existing piles in this manner I was able to trace changes over time, interplay between family members, and sub-concepts within each subject

area. The final coding scheme with an explanation for each category can be found in Appendix C.

Chapter IV is a report of the research findings with quotations to support each of the themes, concepts, and sub-concepts. Sections about the children will be supported with quotations from both the children and their parents. The children's statements present their individual perspectives and the parent's quotations serve as further support by providing a participant observer's view of how the child handled each phase of the disease process.

CHAPTER FOUR

RESULTS

This is the story of the children and their families. The major concepts, reactions and interactions, pain/sickness, hospitalization, baldness, fear of death, and actual death, will be discussed using the words of the participants to support the findings. Each concept will be discussed in relation to the four contextual layers: children, parents, institution, and community.

In some cases, the concept being discussed will not apply to all of the participants. For example, discussion about siblings only applied to 8 of the 10 families, and the data about actual death only applied to 2 families. This fact makes reporting quite cumbersome if exact numbers are consistently given. Therefore, to avoid continually reporting that "7 of the 9 families involved reported...", I will occasionally employ the terms "some," "many," and "most," which will correspond with less than half, half, and more than half. The primary objective of qualitative research is to report participant's personal experiences rather than numerical data (Strauss & Corbin, 1990).

The first concept, "Reactions and Interactions", includes all of the data about how the children and their families thought, felt, and acted throughout the disease process. During the first interviews I noticed that participants reported differing thoughts, feelings, and actions that could be divided into three separate time periods.

Their reactions and interactions changed dramatically as they passed from diagnosis to treatment and then to completion.

For the purpose of this study, the diagnosis phase began when the parents first learned that their child had cancer and ended when the first phase of chemotherapy had assisted the child in reaching remission for the first time, a period of one or two months. The treatment stage began with remission and lasted until the chemotherapy protocol was completed. In most cases, treatment lasted for two or three years depending on the type of cancer and the stability of the remission. If children relapsed, treatment was restarted.

The completion phase began when treatment was over and continued until the family had completely resolved all fears about the child's future. None of the families interviewed had reached the end of the completion stage, although some of the children had been finished with treatment for more than two years. The report of research findings about reactions and interactions will be organized around the three phases of the illness process with a discussion of each of the contextual layers presented for each phase.

Reactions and Interactions

The Diagnosis Phase

Children. During the diagnosis phase, the children were very ill. Some were semi-conscious by the time of admission, with symptoms such as fever, extreme fatigue,

bone pain, and headache. Upon admission to the hospital, they were subjected to a battery of painful diagnostic tests. Soon, chemotherapy was begun, and they developed the additional symptoms of vomiting, weakness, and loss of appetite. For most of the children, the diagnosis phase was the lowest point they would experience throughout the whole ordeal of having cancer.

When asked to describe how the child in the book felt about learning that she had cancer, the children attributed feelings of sadness and anger to the child in the story. They were unsure, however, about who the anger should be directed toward.

How do you think Susie felt when the doctor told her that she had leukemia?
(Interviewer)

She got very disappointed, and she didn't believe him, and she cried a whole lot.
(Catie)

How do you think Tommy felt when he found out that he had leukemia?
(Interviewer)

He felt pretty sad and mad. (Andy)

Who was he mad at? (Interviewer)

No one, really. (Andy)

The children were frightened during this time. They understood that they were seriously ill, because they saw their parents crying.

How did Tommy feel when he saw his mother cry?
(Interviewer)

He was real scared because he never saw her do it before (Andy).

The children were angry about the pain and sickness that they experienced, and they felt helpless to defend themselves against the medical staff who invaded their hospital rooms with an alarming array of medical equipment.

One time I was getting sick, and I asked them to stop so I could get sick, but they wouldn't stop. They just kept hurting me, like they didn't care I guess. (Renee)

The parents tended to describe the children as angry and withdrawn, often focusing on the television and refusing to acknowledge visitors.

During the first hospitalization he focused on TV a lot. He just kind of shut everything else out. If anyone needed his response, they had trouble getting his attention. (Alex's mother)

At first he had a lot of anger within, because a lot of times he would not cry out or anything, he just sort of had a rage. But I would leave him alone, and he would come out of it. (D.J.'s mother)

Some of the children were quite unruly, screaming at doctors and nurses and physically fighting anyone who attempted to examine them. Catie's mother reported:

Catie wouldn't react right. She fought everything. She was real mean, and she wouldn't take her medicines. She would holler and tell me she hated me, because I'd have to hold her down and force her to take the pills. Sometimes she'd kick me in the stomach, and I was still real sore from the C-section, and I'd feel like I was going to pass out.

One child suffered nightmares and woke up screaming and crying. He begged his parents to let him stay home when he was faced with a return to the hospital or clinic for treatment. Many of the children seemed confused about why their parents failed to protect them from the painful "attacks" at the hospital. One child screamed that she

hated her "mother and father, her sisters and brothers, the doctors and nurses, and God."

Parents. All of the parents described themselves as being "in shock" or "numb" when they were told of their child's diagnosis.

Well, when we were told, we didn't break down and cry or, you know, scream and holler or anything. We were kind of numb to some degree. (Molly's father)

When we got to the hospital the first time, we were thrown into making some decisions immediately and we weren't over the shock of it all yet. Then after a few days we got into the swing of things. (Brenda's father)

At the time that they told me I don't recall feeling any emotions at all, not at that time. Then several days down the road I can remember just totally falling apart to a total stranger. I remember, the enormity of it all just finally hit me. (Renee's mother)

Even those who had suspected that something was terribly wrong with their child were quite shocked by the actual diagnosis of cancer. Most of the parents recalled having difficulty understanding what the physician was trying to tell them. They heard nothing after the words "your child has cancer". This reaction served as an emotion focused coping response (Lazarus, 1984) protecting them from the full realization of what lay ahead. After a short period of not being able to think or understand, they began to engage in problem focused coping (Lazarus, 1984) by marshalling support and preparing to fight the disease.

My mom was with me, so she called my sister and said, 'Call everybody!'. And then she called my dad and told him to find my husband, and get him to the hospital. (Brenda's mother)

The first thing I did was call my husband and told him to call everybody. He took care of that while I took care of Lisa. (Lisa's mother)

The parents expressed a need to be surrounded by loved ones who could give emotional support. They also needed physical assistance in the form of help in arranging for the care of siblings, reporting absence at work, and delivering personal supplies and clothing from home for the hospital admission.

There was also a very real sense of "rolling up the sleeves" and going to war with the cancer cells. Mothers tended to devour reading materials in an effort to learn as much as they could about the "enemy" and the "battle plan" that was ahead.

I was devastated. I know I cried for two days, and then I got down to the business of finding out everything there was to know. (Camden's mother)

I learned all the procedures like how to clean I.V.'s and everything. I mentally took notes on everything. I wanted to see everything they did to him, and I wanted to see how he did. I had this need to see everything. I even asked if I could see his tumor. I wanted to go down to the operating room and look at the actual tumor. I wanted to see what it was that did this to him. (Brad's mother)

Fathers, on the other hand, tended to feel the need to "be strong" for the family.

It hit me for a few moments, but then I thought, 'If you are not strong, you are not going to survive. And he needs to be a strong kid so he can survive.' I thought if we fell apart, then he would not be strong. (D.J.'s father)

Well being the husband and the father, I have always felt that I had to sort of lead the way through this thing. I didn't feel that there should be any chance for Andy to see that any of this bothered me. So everything...I took the position that everything was going to be A Ok cause Dad said it would be. That's pretty much the way it went all along. (Andy's father)

Soon after the cancer diagnosis was made, the parents began to feel very guilty. They wondered why they had not noticed the symptoms earlier. They worried that the high voltage electric lines near their home or the weed killer they had spread on the lawn had caused the disease to afflict their children. Some worried about their genetic backgrounds. One mother had several relatives who had died of cancer, so she blamed herself for her child's fate.

I think my wife felt a lot of guilt because of so much of it (cancer) being in her family. And my guilt about it was that we had had an exterminator in NJ, and that I used a pesticide on my lawn in Chesapeake, when we lived there. (Andy's father)

Lisa's mother was concerned that the stress of having an alcoholic father in the home had led to her daughter's cancer.

I've often thought when I look back on the 3 years before she was diagnosed, things were pretty tense. I feel like all that stress, she was probably feeling the tension there. I don't know if that could have contributed, but I thought about that.

Renee's mother concluded that her daughter was given cancer because she had always, secretly, preferred her son.

I felt guilty at first because I had always favored my son. He was the smart one, and he made good grades in school, and probably he was the one that got all the attention. I think everyone felt guilty, because they felt like, maybe it was because we weren't giving Renee as much attention as Christopher.

Along with the guilt feelings, the parents became aware that they were very angry. They began to feel that no matter what they had done, it was not fair that their child had to

suffer through the ordeal of cancer. Some directed their anger at God or fate for visiting the disease upon their child. Others just felt a generalized anger that was difficult to diffuse.

I think the biggest thing I found was my anger at it all. We went to a retreat and they were talking about the difference between anger and rage. He said that anger is when you can direct it towards someone or something, but rage is when it's just all encompassing, and you have no idea who to direct it toward. And I thought, I had them both at the same time. I was very, very angry with God, but I was also outraged about the whole thing, you know? Like I needed a hundred people to blame, and there weren't enough around to pick. (Brenda's mother)

I was feeling a lot of anger and a lot of hurt. You know, a lot of 'Why me?' feelings. I felt that we had just made the move with my company and came down here, and our whole life was going to change around. I had left management and gone back on the road, just so I'd have more time to be with him and then this. It really bothered me a lot. (Andy's father)

Many of the parents directed their anger at each other, because each had a different way of coping with stress and each believed that his or her way of coping was the best.

Husbands tended to accuse wives of "overreacting" because mothers directed every fiber of their being toward the sick child and the defeat of the cancer.

It was just total--I don't even know how to put it. It was just all the time, all your energy, all the physical, mental and emotional--you just felt drained all the time. Like you have no strength to do anything other than get her to the hospital and, get her home, and that's all you could do. The whole world revolves around the sick child, and it's almost like you're not really alive, you just keep moving because you have to keep going. (Molly's mother)

I couldn't understand why she just put on blinders and just ran forward, straight into a brick wall, and without seeing anything on either side. Just kept running straight. That's what she was doing. She was running wide open in one

direction, and that's all. She was totally shutting everything else out. (Andy's father)

Some of the wives were angry at their husbands for not taking the problem seriously enough. They believed that the husbands demonstrated lack of caring by not reacting in the same way they did.

We had such separate, extreme different ways of handling it, that I'd be so angry at him, and he'd be angry with me for my way. And I thought I should feel the way he does, and I thought he should feel more the way I do, and it was real hard. We couldn't talk about it for a long time because it would just be a big fight. (Andy's mother)

There were problems with communication. I don't know if it was male female differences or what, but we just looked at everything in a totally different light. The things he was concerned about, I thought, 'Huh?'. And the things I was concerned about, he thought were strange or trivial or whatever. It was like we were in two totally different worlds. (Molly's mother)

Mothers tended to think of the cancer in terms of a life long problem, while fathers were more likely to think in terms of a "cure". This disparity in viewpoints was grounds for resentment between parents.

I was trying to learn everything I could, because I felt like that was the best thing I could do for Andy. But he (the husband) didn't want to know anything about it. He just said, 'Everything's gonna be fine.' And that just made me so angry, because I didn't think everything was going to be fine. It just really made me mad. (Andy's mother)

I met with the doctor and there was a lot of things being said about a cure. She kept using that word. And my wife said, 'No. They're not using that word. I don't know why you think she's using that word.' And it was a real barrier between my wife and me. So I went back to the doctor and I said, 'Look. Are you telling me that you are gonna cure my son, or are you telling me that you're

gonna treat my son?' And she said, 'No. We're gonna cure your son.' So then I had her go back and talk to my wife. (Andy's father)

Part of me wanted to believe that she was going to be alright, but there was this other part of me that was just so angry for having it happen. I couldn't understand why he was taking it so well. We had just bought a new house, and it had a front porch. I had had visions of us sitting out on the porch on white wicker furniture after all the children were in bed. It would be the perfect life. Then the first time we got a chance to sit on our front porch was two nights after we brought her home from the hospital. I'm sitting out there crying my eyes out and thinking, this was not the way I wanted it. And he was so calm about it. He was like, 'She's going to be fine.'. And I think that really kept us separate for awhile, because I could not accept his--I was so angry with him because I thought, how can you just blindly say, 'Oh yeah. Everything's going to be fine.'? (Brenda's mother)

In one family, however, these roles were reversed. It was the father who was fearful of the child's death. He was so certain of the child's impending death that he continually followed the child around taking pictures. The mother, on the other hand, took on the role of "the strong one," and was fiercely optimistic. She refused to cry. She refused to even consider the possibility of the child's death and she banished from the hospital room anyone who cried or acted as if the child might die. The difference in the parent's coping styles eventually contributed to divorce. The child's cancer may have allowed Brad's mother to see her husband in a new light. She said that she considered the father to be weak and could no longer respect him as a person because of the way he reacted to the son's illness.

My husband was like a little scared child. I got angry at him for not being able to face it. He couldn't talk about it. Anytime we had company, he couldn't face them. He couldn't even answer the phone. He was more or less burying him and

I said, you know, if he didn't change his attitude, I didn't want him around. We went to a marriage counselor, and she said she thought that I hadn't forgiven my husband for feeling differently about all this than me. But I said it was just that there was a time that we all needed him, and if he could have just given five minutes of positive instead of months and months of negative, maybe the marriage could have been saved. (Brad's mother)

Another couple realized that their marriage was in trouble because of the resentment they harbored for each other, but they began seeing a marriage counselor and were able to save their marriage. All the couples expressed that the experience of having a child diagnosed with cancer placed a strain on their marriage.

In the beginning, we were never together. It was always she was there, and I was home, or I was there, and she was home. The only time we got to talk was when she would come up to relieve me, or I would come up to relieve her, and we would go down to the cafeteria to talk. (Catie's father)

Having time for us was a problem, because when this happened, we had two, almost three kids, and then in the midst of her chemo, there was the third one who needed everything. And there was just, physically, no time for us. But then it became emotionally safe for us not to have any time. You know, I was just total mother and caretaker, and he was just total breadwinner. It was almost fake to, uh, have relations. Unfortunately, it was several months before we realized what we were doing. But we've been going to a marriage counselor and things are getting better. (Brenda's mother)

We'd only been married a year when this happened, and it has really put a strain on our marriage. (Camden's mother)

Well every person has stress against them. There's 5 of us in this family, so you have 5 stress problems and none of them are alike and they all clash. I mean, nobody is the same. So if somebody is in a higher stress, then you're gonna have big problems. Someone is gonna erupt. (Camden's step-father)

In the midst of overwhelming stress and marital difficulties, parents reported there was also the problem of what to do with siblings while parents spent long hours at the hospital or devoted time at home to caring for the sick child. Siblings were usually shuffled from one neighbor or relative to another while the sick child was in the hospital.

Once the sick child was home, the siblings felt isolated because the parents devoted most of their time and energy to the care of the sick child. Siblings were jealous of the attention the sick child received and they did not understand the crying, the gifts, the frequent hospitalizations, and the fear they saw on their parents' faces.

Her brother and sister didn't really understand. They threw fits. They didn't like staying with other people and neither one of them had any compassion for Catie. They were jealous of the attention she was getting. They said they wished that she would die. (Catie's parents)

Her brother told her one time that he wished that she would die from the cancer. And I thought, oh, if anything ever happens to her, how will this child deal with that? I thought that was the most terrible thing a child could ever say to his sister. But he was very angry. All of a sudden she was what everyone's world revolved around and he was just kind of a secondary person who was there. It was like, who's gonna watch Chris this week while we go to the hospital? He was just tossed everywhere. I think things are a little better between them now, but not much. (Renee's mother)

Parents felt guilty because they realized the confusion and hurt of the siblings, but had little energy to change the situation. Siblings who had relied on mother for their daily care and support, now saw their mothers engaged, full-time, in the battle against cancer with little time and energy for other things.

I was so numb, all I could see was Andy, and that's all that mattered to me those first few weeks. My husband and my daughter were healthy and they were going to be fine, but Andy needed me, and that's all I focused on. I didn't care about anything else. So I shut them out, I didn't try to take time to spend with Cherie, and I didn't go out of my way to speak to her or send her little notes. I mean, I felt like they should understand. This is our son! My son needed me. I shouldn't have to explain myself. (Andy's mother)

Many mothers reported feeling guilty about siblings' feelings of isolation, but believed that the needs of the ill child were more important than those of the children who were only hurting emotionally. Unfortunately, this belief proved wrong, as will be seen in the findings of the completion phase. In many families, the child who had cancer has completed treatment and is doing well both physically and emotionally. However, parents report that the siblings continue to suffer emotional scars.

Institution. According to the nurse practitioner, the personnel at the medical center offered various types of support to the children and their families. Most importantly, they offered the best possible care they could for the child and demonstrated much concern for the whole family, both physically and emotionally.

Parents agreed with the nurse practitioner. One of the things that was appreciated most by the parents was the amount of information they were given. They reported that they were taught about the disease itself, the medications, the care of the sick child, the tests used to gauge treatment success, and the side effects that could be expected. They were given a great deal of reading material to supplement the verbal teaching done by the unit nurses and the nurse practitioner.

The hospital provided a natural place for exchange of information between families. The pediatric unit at the medical center is located in such a way that all the children who are hospitalized share the same floor, and parents share the same lounge, kitchen area, and nurses station. It is not unusual to have children at several different stages of cancer treatment in the unit at the same time.

Parents who had been dealing with the disease for a while tended to seek out parents of children who were newly diagnosed to "show them the ropes." They shared information about who to trust, what to expect, and when to worry. Some parents, during the diagnosis phase, eagerly sought such information.

I think the worst thing during the first admission was how isolated we felt. We felt very alone. They put the cancer kids in their own rooms because their blood counts are so bad, so you don't meet anybody. So we were sitting there like, well, we want to meet somebody who's surviving so we know what you do to survive this. But nobody was there, and that was really difficult. (Brenda's mother)

Others resented the information they were given by other parents. They wanted to trust the medical personnel fully in order to deal with the immensity of the problem they faced. When more seasoned veterans told them to be wary about trusting, it took away their basis for faith and left them with many fears about their child's well-being.

There was one person up there, (I shouldn't use her name), but she was heading up the support group at that time and her daughter had leukemia. She came to see me that same night we had found out the diagnosis, and I was never so glad to see somebody. Here was a woman who's child has leukemia, and she was still walking around and looked fine. But as she sat there and talked, the more she talked, the more scared I got. She had such a bad opinion of the medical center, and the doctors and had a negative feeling of what was going to happen. It was

mind boggling. I mean, it's bad enough my child had cancer, and now you're telling me that I shouldn't trust anybody. It was just too much. (Andy's mother)

The nurse practitioner at the medical center assisted the parents in coping with cancer by making referrals for the families. She made them aware of the services of the American Cancer Society and community groups that provided special trips for families. Most of the families were given week long trips to the beach, and Disney World, and various one day outings to baseball games and other activities. These excursions provided a time for the whole family to enjoy each other. They were literally a "vacation from cancer," because the family was able to spend time together without concern about money or treatment schedules. The only objective was family fun.

Community. All of the families interviewed reported that friends, family, and neighbors were very generous and supportive during the initial phase of their ordeal with cancer. Families came home from trips to the hospital to find their houses clean and dinner on the table. People were willing to help out by caring for the siblings, taking them to and from school, fixing meals, or anything else that needed to be done.

Many families had relatives who came and stayed during the first weeks to help and offer support. Co-workers and supervisors were lenient about letting parents miss work. In 2 cases, churches and local civic groups held fund raisers to assist with the medical expenses.

In short, the families enjoyed a great deal of support during the diagnosis phase. Unfortunately, this was short lived, as will be seen in the subsequent phases. People generally lost interest once the child was safely in remission, and they forgot about the continuing struggles of the family in need.

The Treatment Phase

Children. The treatment phase began when the children achieved remission and ended when chemotherapy was completed. Depending on the treatment protocol for each child's particular illness, this phase could last from one to three years. During remission, the children had no symptoms of the disease and were essentially healthy. However, all children were at risk for suffering a relapse. For those children who did not relapse, their only health problems were chemotherapy related. Each chemotherapy treatment was followed by hours of nausea and vomiting. The children were receiving treatments approximately every three weeks.

Chemotherapy is also problematic in that it damages the bone marrow, causing a depletion of red blood cells, white blood cells, and platelets. This places the child at risk for anemia, infection, and hemorrhage. Consequently, it is not unusual for the children to be admitted to the hospital once or twice during the treatment phase for pneumonia or sepsis in addition to regularly scheduled admissions for the administration of chemotherapy.

Despite these problems, the treatment phase was a time when life returned to near normal for the children. They returned to school, and although they were often bald, they were able to play and function normally between treatments.

It was during this phase that the children began to take their disease in stride. They learned the hospital routine and became more comfortable in that environment. They learned that the doctors and nurses were not the enemy, and they developed their own explanations for the things that were happening to them. All of the children had some explanation as to why the medicines that were supposed to make them better actually made them very sick and caused them to lose their hair.

You get sick and lose your hair because the medicine is so strong. It really is making you feel better, but it takes a while. It's for your own good. (Camden)

The medicine makes you sick because it's so strong. It has to be strong so it can take a bad cell and throw it out. (Brad)

Well, some medicines will make you vomit or whatever, but that's because your stomach doesn't like them. But really they are making you better by giving you this for your cancer, even though you may be vomiting. (Molly)

Well, you know when your getting sick, that it's working. (Renee)

The children spent a great deal of time during the treatment phase trying to come up with an explanation about why they had developed cancer. All of the children expressed a desire to understand why. Many had come to the conclusion that it was some sort of punishment, but the deeds that they believed may have led to their unfortunate fate were

trivial in comparison, and they realized it. They expressed the view that if the cancer was their punishment, then God was being too harsh.

Did you ever feel that this cancer was some sort of punishment for something you had done? (Interviewer)

Yeah, it was like, when I had done something wrong--now I know why this happened. But it's like, when I break a glass or something, it's like, you've got a right to punish me, but not this bad. (Brenda)

Yeah. It's like, can I make it up? I mean, I'll clean my room. (Brad)

Well, I used to, kind of not listen to my mother, and I wondered if, like, God was just making me feel sorry for what I did and stuff. (Renee)

One child used the interview session as an opportunity to find the answer to the question she had long wondered about. When talking about the little girl in the story, Catie was asked what the little girl should tell her friend, Debbie, when asked why she had been in the hospital.

She should say, 'I have leukemia'. (Catie)

And what if Debbie said, 'What's leukemia?'. (Interviewer)

Well, that's a kind of cancer. (Catie)

And what if Debbie said, 'It's cancer?'. (Interviewer)

She'd be thinking, 'How did you get that?' (Addressing the interviewer) I want to ask you something. How did I get it, anyway? (Catie)

The children demonstrated a rudimentary understanding of the mechanics of their diseases. They realized what a "low count" meant, they understood that a relapse was very bad, and they knew why they were given various treatments and diagnostic tests.

I had to get blood put in me, platelets put in me. I had to have four little baggies. They had to do it because my temperature went up and down, and I was real tired. (Camden)

Andrew explaining a bone marrow aspiration:

Well, first you get numbed in the back and then the bone needle is put in there, but you don't feel it. Then the doctor pushes in and out to get living white cells. Then he puts some medicine in, then pulls it out. It hurts really bad, but don't put that in the book cause I don't want the kids to get scared. It lasts about five or ten minutes, I don't know. It feels like a long time, and you get real sweaty. (Andy)

During the treatment phase the children did not want other children to know that they had cancer. They feared social isolation due to classmates thinking they were strange and refusing to be their friends. Some classmates expressed concerns about "catching" the cancer and treated the sick children like lepers.

A girl named Felecia told everybody that if they got near me, they'd get it. And, I mean, you just tell them that it isn't true, but they believed Felecia and stuff. Our teacher got really mad. The 2 of us would be sitting down there, and everybody else would be over there talking about us. Like the reason that Jessica's sitting with me is that she has cancer too, but she won't tell anybody. Our teacher used to just come over there and sit with us. (Renee)

The children did not keep their illness secret from adults. They were quite open in telling adults about their cancer, but concealed the fact from their peers when explaining the reasons for their baldness and frequent absences from school.

This could be explained by the difference in reactions between adults and children. Adults tended to react by showering the children with gifts, love, and extra attention, but classmates tended to alienate the sick child.

I didn't like to tell my friends because they'll kind of look at you like, 'You're some kinda weirdo. You have cancer.' And you know, it's like they look at you like, just because you have something wrong with you, you're some kind of Frankenstein, and there's something wrong with you. (Brenda)

While the children seemed to enjoy the extra attention they gained from being sick, they were also aware that their illness had caused major changes in the family. They were aware of the jealousy and rivalry between siblings, the financial pressures on the parents, the days missed from work, and the overwhelming stress experienced by everyone. They also realized that they were the cause, and this brought on feelings of guilt.

Many of the children expressed some degree of guilt, but most stated it indirectly. Two children expressed their feelings directly and demonstrated an amazing level of insight. Renee declared that if she relapsed, she would not receive treatment, because she did not want to put her family through the agony a second time. Of course, she was unable to understand that her death would have had more of a negative impact on the family than fighting the disease a second time.

Your mother told me that if your cancer were to come back, you have decided that it would be better for everybody if you didn't have treatment. Is that what you think? (Interviewer)

Yes. When I'm sick it's like, 'Our world is Renee'. (Renee)

Brenda stated the guilt she felt even more directly and itemized the damages she had caused.

When I saw my parents cry I felt like everything was my fault, because I was the person who had cancer. I was the person who had to have all this treatment. I was the person who was costing all this money, and I was the person who was causing all these problems. (Brenda)

Parents. Parents described the treatment phase as a time for settling in and incorporating clinic and hospital visits into weekly routine. Life settled into a fairly predictable schedule, and parents had a chance to regroup from the diagnosis phase.

The problems of balancing jobs, family, and finances continued as during the diagnosis phase, but parents reported feeling less stressed, because the child was in remission and no longer in imminent danger of dying.

The parents were vigilant about watching for signs of relapse, but the child was being examined regularly at the hospital, so the responsibility of watching for a relapse was primarily that of the health care team rather than the parents. Each hospital visit brought renewed hope as the parents were reassured that the child remained in remission.

She had a virus in July, and she ran a high temp, and I was really worried. I thought that was the leukemia showing up, and she was supposed to be in remission. She'd only had it a little while, and I was really scared. It seems like I even took her to the emergency room. (Lisa's mother)

It was really relieving, in between checkups you kind of wonder if everything is okay, but then every 3 or 4 weeks we went up there and got another clean bill of health and went on our merry way for another month. (Renee's mother)

During the treatment phase, parents noted a dwindling base of support among friends, family, co-workers, and churches. People seemed to believe that once the child was safely in remission, the crisis was over, and the family was no longer in need of support. Thus, many parents battled feelings of bitterness as they encountered the loss of needed emotional support. This demonstrates the interdependency of families within the social system (Walker, 1985).

They did help at first, but I don't think anybody really understood. They'd ask how he was, and I'd start explaining all this stuff to them; and they would just turn you off and change the subject like they really didn't--they just wanted to know if he was okay, that's all they wanted to know. (Andy's mother)

People are constantly assuming that since you're not in the hospital, or you're not getting socked with a \$600 methytrexate bill--now that that's all over with, everything is back to normal. They say, 'Well, what do you mean you're still having problems? She's cured isn't she?' And we have to explain that she is in remission, but that's not a cure. (Brenda's father)

Unfortunately, there have been times where it's made us really bitter. I mean we find ourselves watching TV sometimes and you know--I remember Jessica McClure when she fell in the well, and the whole country is sending thousands of gifts and money, and she's getting a huge trust fund. And I remember sitting there thinking, she fell in a well. She is perfectly fine. Coming out she is normal. What's anyone doing for us? You know, our whole lives are falling apart, and everybody's acting like, 'Oh well, that's the way it is.' You know, it was really hard for awhile there not to be bitter about what other people got, and that everyone looked at us like, 'Oh, you're still going through that?!' (Brenda's mother)

As the treatment phase progressed over several years without relapse, the parents tended to place a great deal of faith in the power of the anti-cancer drugs. They looked forward

to the end of treatment and the withdrawal of the drugs with feelings of ambivalence. On the one hand, they eagerly anticipated the end of hospital visits, drug side effects, and constant financial worries. On the other hand, they were not anxious to give up the drugs which were maintaining the child's remission.

Institution. The institution continued to deliver the same type of care during the treatment phase that was initiated during the diagnosis phase. Children were seen at monthly or weekly visits depending on the protocol being used. Medical staff members were alert for signs of relapse and supportive of family coping efforts.

Whenever possible, blood tests and routine examinations were conducted by physicians local to the family to spare them the expense and inconvenience of traveling to the medical center. The nurse practitioner made arrangements for the visits and facilitated appropriate exchange of information between the local physicians and the medical center.

The families were also encouraged to attend retreats and seminars offered by various community agencies to gather knowledge about the child's illness and suggestions for how to cope with the multiple problems brought on by the illness. The nurse practitioner made the information about such events available to the families by posting flyers in the clinic waiting room and placing families on the mailing lists of community agencies.

It's been talking with other families that has really helped, because they either have the tricks of the trade or they hear--go to this agency or that agency, and they'll intervene for you or whatever. (Brenda's mother)

The retreats we got into more and more. It was probably bad that we didn't get involved right off the bat. You go and sit down and talk to people. You're exposed to other parents of children with cancer and you see different treatments. You also kind of catch up on the doctors. So you get to learn the newest things in treatment and all that. (Camden's father)

Community. Both the American Cancer Society and Camp Fantastic sponsored retreats and seminars throughout the year as a way of supporting the families. Parents were given advise about how to handle sibling rivalry, how to deal with treatment side effects, and how to handle marital problems. The retreats also afforded the families a time to do things together at little or no cost. Parents reported that both the sick children and their siblings benefitted from these special weekends.

Recognizing the isolation that siblings of children with cancer often experience, Camp Fantastic offered them a special camp. Siblings of the sick child were brought to camp for one weekend during the summer and treated as very special people. They were called the "Top Brass" which was short for brothers and sisters, and given special shirts bearing that name.

One of the reasons we started the sibling weekend is because we knew there were issues where the siblings thought that they were responsible (for the sick child's illness), or that they could catch it, or that the sibling was going to die. There were a lot of issues that siblings were dealing with, and our sibling weekend gives them a chance to get together, and we actually have a discussion about these issues. The kids need to know that they can be a part of a special group too, just

like the kids with cancer. They get their own fancy shirts. It's called Top Brass and they get a Top Brass tee shirt that cancer kids can't have, cause they're not the sibling of a cancer patient. (Camp Director)

The Completion Phase

Children. The completion phase began when the chemotherapy ended.

Therefore, I expected it to be an occasion for celebration. However, interviews revealed that it was a time of many fears, uncertainties, and adjustments for both children and their parents. The children understood and feared the possibility of relapse.

Well, I just think, 'It's not coming back. It's not coming back.' But if it does, it does. I mean, maybe I won't be so lucky next time. Cause I know a lot of kids who got really happy that they were over, and about a year later it came back, and they died from it. So I don't really get my hopes up. (Renee)

All of the children except for Brad, who was the son of the fiercely optimistic mother, voiced concern about their cancer coming back. In the interviews, the children often spoke in terms of "when my cancer comes back" rather than "if my cancer comes back". When I pointed this out to them, they said that they were pretty sure their cancer would come back. Two of the children had already made mental plans for what they would do when the cancer did recur.

Catie told her mother that when her cancer came back, she would be more cooperative with the treatment.

She'd just gotten an allergy shot. She said, 'Mama. I'm getting used to these shots, so when my leukemia comes back, I'm not going to act the same way I did before.' (Catie's mother)

Renee told her mother that when the cancer came back, she would refuse treatment, because she did not want to put her family through the whole ordeal again.

Some of the children also showed a degree of vigilance about their own bodies, and became quite concerned if they bruised too easily, or if they developed any of the symptoms that reminded them of their first experiences with the disease, such as fatigue, bone pain, or loss of appetite.

Each time she feels bad, she worries about it. I mean there will be times when she comes in and she says, 'Mama, look at all these bruises on my leg. I think my counts are down.' And I have to tell her, you know, not to worry about it. I know her counts are fine now. But there are things that she worries about.
(Renee's mother)

Some of the children also had a difficult time adjusting to the loss of attention that occurred, because they were no longer ill. Being sick with cancer had brought a certain notoriety, and some of the children missed feeling special. They responded by becoming very open about their experiences. Those who, during the treatment phase, had concealed their illness from classmates were now saying, "Hey! Did you know I had cancer? Let me tell you all about it." Camden's father noted:

Now he goes back and tells everybody the gory details and everything, step by step. Like when we did all that stuff on Tuesday, he went back over here to day care, and he explained everything in detail.

Renee's step-father reported:

She just went into a new school district and it came up that she had had cancer, and she brought it up to the teacher, and we remember getting a couple of phone calls, and she became like an overnight celebrity for a little while.

Some children took their x-rays for show and tell and others showed their scars.

Some people, they don't make fun of my scar or nothing. They just, when I'd be swimming, they'd go, 'Oh, what happened to your stomach?' I'd just tell them the whole story. (Brad)

The children eventually learned to deal with the changes in their lives and resumed normal activities. Each child was encouraged to continue attending Camp Fantastic for 3 years while life gradually returned to normal.

Molly and Brad, who had been off treatment for the longest period of time at the time of the interviews had found other ways to feel important. They spoke of their cancer experiences as part of their past and even found that they had forgotten certain details as they tried to talk about their experiences for the interviews. They seemed, from outward appearances, to be quite well adjusted and happy, in spite of the trauma of their past.

Parents. The completion phase was difficult for the parents also. Although their schedules returned to normal, and they no longer had to make frequent trips to the medical center, they too feared relapse. They had come to trust the power of the chemotherapy to keep the cancer at bay, and now they felt that their children were defenseless and apt to relapse.

I guess I felt more at ease when he was on treatment. When he went off it, I was like, 'Oh my goodness, he's off it. Is the cancer going to pop up again?' (D.J's mother)

I'll feel a little more comfortable after the first year off treatment is over. Because now is the time that if something is going to happen, it would happen. There's no treatment against it right now, so it's to the point that if it's going to come back, it would be more likely to come back now. (Andy's mother)

We were real scared (when she went off treatment). You know, we were thinking, this is what's keeping her alive, this preventative type of treatment. So we just figured that each time we went back up there, it would start growing. (Molly's father)

The parents were very protective of the children. They seemed to want to guarantee that no further harm or illness would come into their child's life. They believed that their children had been through enough, and they were responsible for protecting them from further trauma. These feelings were often spoken of in terms of being unwilling, or unable, to allow the children "out of their sight". Mothers, especially, were quite uncomfortable about letting anyone else assume responsibility for their children.

I let her go to church camp last year, and I let her go this year. Last year I worried about her more than I did this year. Of course, she had just gone off of her therapy, and I didn't know if she got hurt if they would do the right thing. I mean, would they really know what to do and all this. (Lisa's mother)

Andy's mother attributed her insecure feelings to her child.

He's real excited about it (going to Camp Fantastic), but Andy is the type that is very attached to home and Mom and Dad, especially Mom, so he'll probably get home sick. I'm real concerned about that. It's just part of his personality. He always was closer to me, and he's just a very sensitive child, more clingy to home. He likes to be home. Home is someplace safe. Maybe he's afraid something bad is gonna happen to him if he's not home.

About three weeks after the interview, Andy decided not to attend camp because he "was afraid he would get too homesick."

Parents were also protective about the physical bodies of their children, especially those who had undergone surgery in the treatment of their cancers.

I worry about him when he rough-houses. I am extremely overprotective when he's out playing with other kids, and I see him rolling around on the ground. I'm out there yelling to get off the ground, and leave him alone. When kids pick on him I'm to the point of being embarrassing. If he gets into an argument with a child, I'm out there telling the kid, 'If you lay a hand on him, you're going to deal with me!' And he's going, 'Ah, mom. Come on!'. My new husband says I've got to let him learn to do this on his own. But I say, 'Do you know what will happen to him if he gets hit?'. I'm pathetic really. (Brad's mother)

At the same time the parents were feeling overprotective, they were also trying to reestablish discipline with the now well child. Parents who had been afraid that their child would die, reported blatantly indulging the child with the belief that if the child survived, they could undo the damage later. Now that the child had finished treatment and was apparently well, the parents had the job of "unspoiling" the child. Although this was a problem with several families, Renee's mother was most expressive in her descriptions:

That's one of the bad effects, I think, of being a sick child and having so much attention is that when, all of a sudden, she's expected to be a well child and be normal, she didn't know how. I didn't know how to treat her now. You know, we just literally worshiped the ground she walked on and spoiled her shamelessly. We didn't know what time we had and at that point I thought, 'I'll worry about it later. We'll undo the damage later.' Well, the damage became a handful later, but that's one of the things we're working on now.

School is going to be one of her big problems for awhile. I've been trying to teach her to get attention from being intelligent, and doing good work, instead of being class cut-up and class cutie, which is, unfortunately, how she kind of edged into getting extra attention after all her treatments were over. She is developing several distinct interests now. I've talked about getting her into dance class, and of course she has her little pets, and she's got more toys than any child should ever have. But people in the church and friends and neighbors and family really flocked to her while she was sick. And while, at the time I think it was an integral part of her recovery, once the furor of her being so sick died down, she had a void there, and it was just real difficult for her at times to know how to act.

As time off treatment spanned a year or more, most of the parents began to gradually relax and put the cancer behind them. Visits to the clinic for check-ups stretched to 6 month intervals and family life gradually returned to normal.

Four sets of parents even came to the realization that their experiences with cancer had had positive ramifications. These comments were totally unsolicited by any question in the interview. They were usually verbalized at the end when I asked, "Is there anything else you can tell me that will help me understand what you have been through and how you have coped?" The testimonials were a tremendous illustration of the resiliency of the human spirit and the ability of some to find good in the worst of circumstances.

Some parents believed that their experiences with cancer had brought their families closer together.

My wife is kind of emotional, but I would get in a corner and I would grit my teeth and I would shed the tears, but we came through it. I think a situation like that brings a family closer together. It brings you closer to other people too.

When you see someone else who has problems worse than what you got, you feel more comfortable going through with them. (D.J.'s father)

Others reported great spiritual and emotional growth in parents and children alike that would not have been possible without the terrible impact of cancer.

I'm no longer angry at why she got it, at all. And I don't ask, 'Why us?' anymore, because there has been too many positives out of it that, to a newly diagnosed family, you could never say that, but there was good. I'm to the point finally, where I believe God did not give us this or didn't give it to someone else or whatever. I think that because it happened, we have grown in ways we never would have otherwise. We have friendships now with other cancer families that we could never have met otherwise. And those friendships are tighter than any other friendships we ever--I don't think those bonds will ever break. (Brenda's mother)

I think there's no way you can say it didn't help. I think it tests your faith. I had a very difficult time having peace with it for a while. It took a long time to realize that God would use this somewhere down the road, and He obviously has. The friends we have gained from this and been able to share our experiences with tend to bring out the positive side of it. (Molly's father)

Lisa's mother believed that her contact with the resources at the medical center had helped her gain the strength she needed to go through with a divorce to her alcoholic husband.

He was doing all these bizarre things, you know, aside from drinking. He was carousing around and stuff he had never done before. It took me a while, but I started to realize that the whole business was unhealthy, and we were all unhealthy in ways. Sometimes I think that had her illness not come along, that it's been strange in a way, but things would've turned out differently. Maybe we got some help because of her illness because I came into contact with people that I wouldn't have normally come into contact with.

The parent who had the most difficult time during the completion phase was the mother who had been fiercely optimistic about the outcome of her son's illness throughout the entire process. She had repeatedly proclaimed that her child would not die because she believed that he would live, and she believed in the power of positive thinking. She vehemently denied that she had ever feared for her son's death. However, during the interview she continually steered the conversation back to the topic of death. After Brad completed treatment his mother suffered a year of depression. It was probably during that time that she allowed herself to feel all the fears that she had denied up until that time. I believe that she knew she was unable to handle those thoughts during the time that she had to play the role of "the strong one". Her repression of those thoughts was a form of emotion focused coping (Lazarus, 1984).

I cried when it was all over. I cried for probably a year after it was over. I cried constantly at night after it was over. I grieved for the year that he lost. I grieved the year I lost. I grieved the death of our marriage. I grieved. There were so many things that died at one time. That's why I grieved. I had been strong for so long, I just went to being a really big wimp. He completed treatment, and he was in good health. Then I just died. (Brad's mother)

Institution. According to the nurse practitioner, the medical center began to gradually break contact with the children and their families after the completion of treatment. The children were seen initially each month for check-ups. Eventually these clinic visits were stretched to semi-annual and then annual visits for the rest of the child's life.

Community. Parents reported that most of the concern and offers for help from friends and neighbors had vanished by the time the child finished treatment. To those outside the family, the child was essentially well as soon as remission was achieved, and few understood the continued hardships on the family.

Children were encouraged to attend Camp Fantastic for three more years after treatment was completed. This had both positive and negative affects for the children. While they enjoyed the experience of going to camp and renewing friendships each summer, they also came to realize, through going to camp, that not all patients who made it to completion phase stayed in remission forever. Several of the children, when asked if they ever worried about suffering a relapse after treatment was completed, spoke of friends they had known at camp who were fine one summer and then did not return the next summer because they had relapsed and died. During the completion phase, many parents began to "give back" to the community. Alex's and Brenda's mothers served as presidents of the Charlottesville Candlelighter's Support Group. Andy's mother started a chapter of the support group in her area. Catie's mother and father spent a great deal of time helping Camden's parents as they dealt with his relapse and subsequent death. Brad's mother led a community project to distribute food and toys to needy families at Christmastime. Brenda's mother became politically active in lobbying for better insurance benefits for children with cancer, including coverage of

bone marrow transplants. She also became volunteer director of the American Cancer Society's childhood cancer division.

There's still anger at certain things. There's anger at insurance companies and there's anger at society for the way that they look at things, and kids, that kids medical problems aren't as important because they don't vote. Unless the parents do something, and most of the parents are too entrenched in taking care of the kids to get out there and lobby. So, things like that get me angry, and when I get angry enough I get mobilized, and I start doing all the stuff I've done. That's been good for me, it been a way of releasing my anger, you know. And there have been times that I've probably been consumed by it. I have recently pulled back a little. And yet the phone will ring and someone will say, 'I need to find out about a transplant.' What can I do? I'm on for 4 hours, and he knows not to bother me. But, that lessens my anger, cause I finally have somewhere to go with all I've learned, and it gives me time to be grateful that I'm not there. As bad as things might have been for us, they could have been worse, you know. There's others that definitely have it a lot worse than we have. (Brenda's mother)

Pain/Sickness

Children

All of the children interviewed showed a change in their coping behaviors as time went on, as predicted by Lazarus (1984). Parents reported that the children's initial reaction to painful treatments during the diagnosis phase was the same in all the children. They reacted by screaming, crying, and physically fighting, strategies that fall under the Action/Inaction category (Caty et al., 1984). They saw the doctors and nurses as "the enemy" and did everything in their power to resist them.

I was really afraid and didn't think I could go in so a friend of mine went in with her. They had a nurse on each leg and a nurse on each arm, and then my friend was holding her upper chest. I just remember her screaming and screaming, and all the way to the other end of the hall I could hear her. And finally they got it in, but there was one nurse that was really heavy, and she came out literally wringing wet with sweat from trying to hold on to her and the tension and all. It was just horrible. (Brenda's mother)

Later, during the treatment phase, as the children began to realize that the treatments were necessary for life and that the doctors and nurses were not adversaries, different coping efforts were utilized. Information-Exchange and Intrapsychic strategies predominated (Caty et al, 1984).

The most common strategies used by the children during the treatment phase were postponing or directing. Both were forms of controlling the situation, thereby making it seem less threatening. Postponing took many forms. Half of the children interviewed described hiding to postpone inevitable treatments.

I wouldn't let them do it. There was these little slit doors where they kept the towels. I'd hide in there and they'd spend hours looking for me and I'm just sitting in there. (Renee)

Others delayed by asking questions, making the doctor count before starting, or simply saying, "Wait! I'm not ready!" repeatedly.

He postpones everything. 'Well, I've got a question. Let me breathe. Let me do this, let me do that.' He just tries to postpone it. (Camden's mother)

I'd say, 'Wait! Let me count to 10!' And then when they'd get ready, I'd say I had to count to 10 again. Finally, they would just do it. (Brad)

Directing involved orchestrating the event in great detail. The child would tell the doctor or nurse how and when to do each step.

He had to watch. If he could see what was being done, he wanted to see. And he would give them directions on what to do, then he would do it. Um, like with his arm stick, he'll say, 'I'll count to three, and then you can go.' He says it every time he goes, and they all know it. And you have to put the elastic band around his shirt, not around his skin, and he just gives orders left and right. So he feels like he's the boss. (Andy's mother)

He was getting his finger sticks every Sunday. They had one guy over there who didn't know how to stick his finger. Most of them over there know Camden's procedure, but this guy stuck it right in the middle of Camden's finger, and he got mad and said, 'No, you stick it up here.' but the guy said 'No, I do it this way.' So Camden started acting up. (Camden's mother)

Other coping strategies that were mentioned by the children included intrapsychic efforts such as "thinking about other things" and "making the best of a bad situation." They knew the painful treatments would be completed regardless of what they did to fight. As Hamner and Miles (1985) found, all the children reported that parental presence was very important.

There were some procedures that were so threatening that the children failed to show any progression in their coping behaviors. The children seemed to think of the painful treatments as a hierarchy that differentiated between those that they "got used to" and those that never got any easier. Routine injections, venipunctures for bloodwork, and having IV's started were described as "not so bad," and the children were able to cope with these procedures with less fighting as time went on. However, the children

never seemed to adjust to bone marrow aspirations and lumbar punctures (LP). In fact, their coping behaviors seemed to become more directed towards physically fighting with each occurrence.

They used to come for blood tests every morning. I usually screamed and hollered. It hurt. Then after a while they had stuck me so much, I got used to it.
(Molly)

The LP's kept getting harder, because there was much more recollection with each one of them of what it was like the time before. That kept getting worse instead of better. But everything else just continually improved, the bloodwork was much easier as time went on, and she was very willing to have it done.
(Renee's mother)

Without careful examination, this finding seems to refute Lazarus' (1984) view that coping is a process that the individual becomes more adept at as experience with the stressor increases. Prolonged experience with a particular stressor supposedly allows for more accurate threat appraisal and therefore more appropriate coping responses. Upon closer analysis, Lazarus' (1984) theory was actually supported because, it was the increased ability to appraise the level of threat that may have led the children to develop a two tiered level of coping. The bone marrow aspirations and lumbar punctures are much more painful than the other procedures. Perhaps the children realized that they could cope with the less painful treatments by using postponement or directing, but found it necessary to resort to more physical means to cope with the more threatening procedures.

Parents

The parents assisted the children in handling painful treatments, primarily by being present.

She didn't want me out of her sight at all. You know, I had to go to the playroom. I had to go everywhere. It was pretty stressful, and if I did even go into the bathroom and was gone very long, she would come after me. (Lisa's mother)

I told Brad from the very onset. I told him that I would not leave until he left the hospital. I did stay with him, and we beat it. (Brad's mother)

Three of the mothers were unable to accompany their children to the treatment room because they feared they would faint. However, in each case, the father was assigned the role of being present during the painful procedures. None of the children were expected to endure the painful treatments alone. Camden's parents were unable to stay at the hospital with him because of their jobs, but they asked the nursing staff to schedule Camden's treatments in the evening when they were present.

Parents used a variety of methods to help the children through the procedures. Distraction, rewards, giving information, and "talking them through" were mentioned most often. Distraction included talking to the children during procedures, reading to them while they were sick, and using various forms of guided imagery.

One of the things we used to do was to imagine that we were in a pool of water floating on a raft. The sun was beating down, and we'd just go through all the feelings. We just shut our eyes and tried to focus on something else that was relaxing so we could relax. (Andy's mother)

Rewards came in the form of promising ice cream, money, or a special trip after the treatments were over.

The thing I kept thinking about most of the time was, my family would always promise me an ice cream after I got out of the hospital. So I would kind of think about that instead of, you know, thinking about what the doctor was doing.
(Brenda)

Many of the parents believed that their children were better able to cope with the painful procedures because of the anticipatory guidance they had given. They carefully prepared the children for each clinic visit or hospital procedure by telling them what to expect before hand. Parents that used this method of preparation were very concerned about developing a trusting relationship with their children and were understandably upset whenever a procedure was begun before they had had a chance to prepare the child.

We always told him what was going to happen ahead of time. In the hospital it was kind of hard though. Sometimes, in the mornings, they'd come in to draw blood so early. One morning I had gone to the bathroom and by the time I came back she was already in the room trying to fight with him to get it and he was having a fit. I told them, 'Don't do anything to him unless I'm here.' After that they always waited...but they don't see the person. They just see, 'I gotta get this kid's blood and hurry on to the next kid.' (Andy's mother)

"Talking them through" involved assuring the children that they would not be alone, pointing out the positives, and general comfort measures such as holding the children, rubbing their backs, wiping their faces with cool clothes, and enjoying close physical contact.

He'd say he didn't want to do it, and I'd say 'let's pretend like we're playing Pacman and the shots are the Pacman and they'll gobble up the bad cells. Even though you have to get sick, that's Pacman. He's gobbling up the cells and that means you'll be getting better soon.' (Brad's mother)

I remember, we came home on Thursday from the hospital and he had to go back to the clinic on Monday. I was trying to tell him, 'It's really good that you don't have to go to the hospital today, and you have Saturday and Sunday off, and nobody's going to stick you. But Monday you have to go back. But you don't have to stay over night. You just have to get what you need and then come home again.' I tried to dwell on the good parts. (Andy's mother)

Institution

According to the nurse practitioner, the staff of the medical center assisted the children in coping with painful procedures by giving information, promoting therapeutic play, allowing the children as much control as possible, and encouraging parental presence. Children were offered explanations before treatments and allowed to see equipment if they wished. During the procedures the children were told step by step what was being done.

Conversations between the physicians and parents were usually conducted in the children's presence in an effort to keep communication open. However, it must be questioned how much a 4 to 8 year old child would understand of these conversations, since most adults have difficulty understanding medical discussions.

We try to be very open in front of the children. We always talk to the parents when the children are present. The kids need to get used to hearing that they have a tumor or they have leukemia. Even if they don't know what all that means, they still know that they have to come for treatments and as they grow older, they will learn a little more about it. (Nurse practitioner)

During procedures, medical personnel tried to allow children to cope in whatever way they could. Those that coped best by postponing or directing were allowed to do so. Children who chose to cope by screaming and crying were assisted in holding still, and the procedure was completed as quickly as possible to lessen the child's extreme anxiety.

Kids get kind of used to the painful stuff after they begin to trust certain personnel. They get to know you well, and they trust you. If there is a certain person that they've had a good experience with, we'll get that person to do their procedure each time, as much as possible. If that person is sick or on vacation and not available to do it, then that's when we have problems. (Nurse practitioner)

Andy was allowed to direct his diagnostic tests:

Well, mostly when you get the numbing shot, it hurts. So if you've got to get a bone marrow and a spinal tap...well, this is what they do for me..I get them to numb both parts at the same time. So, the numbing shot, you only feel it once. (Andy)

Community

According to interviews with the president of the support group, The Candlelighter's Support Group conducted weekly meetings for the families of hospitalized children to offer support and give information about how to assist children in coping. Some of the meetings included separate sessions for the children, conducted by hospital psychologists to give support and allow the children to ventilate hostile feelings.

Hospitalization

Children

When children were questioned about hospitalization, out of the context of pain and sickness, they spoke favorably about their hospital admissions. Eight of the 9 children interviewed said that they enjoyed being in the hospital and missed it when their treatment was completed. They spoke frequently about hospital play, the close relationship with their nurses, and the gifts and attention they received as a result of being hospitalized.

It was only when specifically asked about painful treatments and sickness that the children mentioned those topics. This may have been a testimony to the resiliency of children, or it may have represented the fact that children were often given anti-nausea drugs which caused them to sleep through the most uncomfortable events of their hospital stays. Some of the factors often thought to precipitate negative reactions of children to hospitalization, such as restricted activity and IV therapy, were the objects of play mentioned by the children.

I remember Sandy came up to the hospital to see me. He was pushing me in the wheelchair because I was too weak to walk. He was making me do wheelies in the wheelchair, and we were out in the hall running into stuff. (Brad)

My mom would push me all over the hospital on my IV pole. I would stand on the bottom and hold on, and she would push me. It was fun. (Lisa)

I would lay in bed, and press my button. The nurse would come in to see what I wanted, and I'd say 'Nothing', then 2 minutes later, I'd press it again. It would really drive her nuts, but I just laughed and laughed. (Brenda)

We used to put on diapers and run up and down the halls of the hospital talking baby talk, and my mom's in the door of my room yelling, 'Renee, get in here!' and she would be looking all over the place, and we would just be running around pushing the IV pole. (Renee)

The nurses played an important role in the children's positive memories as well. The children reported feeling special because the nurses knew them as individuals.

I liked going to the hospital because, you know, I always got to see my primary nurse again. We always traded stuff back and forth, like boxes of chocolate and stuff. That was one reason I was always anxious to go. (Molly)

The nurses brought me food and everything. You could order french fries, sherbet, orange juice, milk, or whatever you want, and they'll give it to you, just about. (Brad)

I like staying in the hospital. It's the best part. The nurses know me, and I get to sleep late and watch TV late. (Camden)

Finally, the children spoke of the attention and gifts they received during hospitalization. Each child was asked, during the interview, what she would say to another child who had just found out that she had cancer. The children invariably replied that the child should not be afraid because "it wouldn't be that bad." Their responses may be explained by the gifts and attention that were showered on them, causing the unpleasant aspects of the disease seem somehow "worth it."

If a kid just got cancer, I'd tell her everything would be alright. That you would probably get a lot of attention and that most of the time you'd--everything would pretty much be alright. I mean, you'd have, like your mom and dad there, and

you'd have your brothers and sisters coming to see you in the hospital and all. When you're in the hospital, that's your time. (Brenda)

When I came home from the hospital, my mom's friends who work with her, they had a van full of toys---two vans.

(D.J.)

I got at least about \$100 or \$200 in the hospital. I bought a bike and a skateboard and everything, and then when I got home, my room was so packed, [with toys] you could hardly walk in it. (Brad)

Parents

Hospitalization was a source of much stress for the parents. They described the hassles of missing days from work, arranging for the care of other children at home, the financial worries, and the tiresome job of fighting the hospital system.

The daily hassles during the hospitalization of the child included rearranging parental work schedules to ensure that someone was with the child at all times. This often led to strains of parental and family relationships since there was little opportunity for communication and caring. Parents felt guilty, stressed out, and exhausted.

Lining up, scheduling how to go places, to go to the hospital to get this done to him, was my job. I'm a supervisor and a very pushy supervisor. If I'm not at work, things don't get done, at least don't get done my way--and it's very hard for me to take off. but, I had to take off. (Camden's father)

After the first couple of months, I had to go back to work, so we would take turns. I would go up on the weekends and stay, and she would come up on Monday to relieve me. And, you know, it wasn't the happiest of marriages. The little things would really aggravate us and cause tension. There were two kids at the time and she was always with one, and I was with the other. (Molly's father)

Financial worries were a constant cause for concern among the parents. The fathers frequently took on the role of worrying about money while the mothers spent their time learning about the child's care and providing support. During the diagnosis phase, financial worries were overshadowed by the process of coming to terms with the child's illness. It was usually during the treatment phase that money became a prominent concern.

At first, when you're first diagnosed, you don't even think about money. You don't even think about your insurance. And you never consider what it's all going to cost. There's no point to it. You just want your child to get well. A year later your going 'I need someone to take care of these bills!' After a while you begin to feel like the illness is not your battle, it's the money that's your battle. You know, she might recover from the disease, but never from the financial end of it. (Brenda's mother)

In the beginning almost everything is blocked out, but in the back of my mind I was thinking about finances. I was thinking, 'these bills have got to be paid. I've signed all these papers saying that I'm going to pay them.' (Catie's father)

In addition to the financial worries and the daily hassles, parents felt a certain wariness about dealing with the hospital system. All hopes for their child's survival rested on the competence of the medical team. However, early in the treatment phase, parents began to realize, through observation and conversations with other parents, that total trust in the medical team was ill advised. They began to stand vigil over their children with a degree of caution, watching for medication and treatment errors, and standing guard against the constant intrusions of interns and residents.

You had to have a parent or someone there at all times. I'm not blaming anyone. So many kids are sick, and they are short handed. But you need to be there. Sometimes they could make a mistake. They had interns and things. (D.J.'s father)

They'd bring 8 or 10 people in the room, you know, and everyone would have to listen to his heart. Everyone would have to feel his neck. Everybody has to poke his stomach. And then they all stand around and talk about him. I understand they need practice, and that's OK. But they've got to help us, too. It really made me mad. I didn't like it at all. In the beginning you're afraid to say 'No'. 'Am I allowed to say, No?' And then you learn that you can say 'No' to them. (Alex's mother)

I wouldn't say we were fighting the system. I would say we were controlling the situation. There is a difference. Because if you fight the system, they treat you like royal shit. But if you control the situation instead, let them think that you're thinking along their lines, that you're working with them... (Andy's father)

It is a fight though. It's a fight to have to worry about making sure all of this is taken care of in the right way, and worrying about what they're doing, and worrying about your son. One time they gave him too much Atavan. They weren't sure of the dosage, so they went by weight and height and they gave too much. I was terrified. I was watching his chest rise and fall to make sure he was still breathing. I thought he was going to die from overdose. (Andy's mother)

Parents perceived that their most important responsibility during hospitalization was supporting their child. In spite of all the hassles and worries, they felt that their presence was the most important factor in helping the children cope with hospitalization. By being there, they could learn, protect, and support.

You just do it. You do it for them. A lot of times you get your strength from them because you see them going through all this like a trooper. And you think, if he can do that, I can do anything. There's just no question. Like the times when they had to run the vincristine and the methylnatrexate together. It would make him so sick, but it was only for one day, so we'd just say, 'We'll get through

this, Andrew. We've just got one bad day and we'll get through it together'.
(Andy's mother)

Institution

The staff at the institution assisted the child and the family in coping with hospitalization in the same way that it assisted with pain and sickness. They gave information, promoted therapeutic play, gave as much control as possible, and encouraged parental presence.

Community

Of the three community agencies represented in this study, only two organizations were directly concerned with helping the families cope with hospitalization. The American Cancer Society provided about \$200 per family for transportation, parking, meals, and lodging. The Candlelighter's Support Group held monthly meetings at the hospital to assist parents in coping with cancer related issues. Nine of the 10 families attended support groups at least once. Only 4 families became actively involved.

It was through the support group meetings and informal conversations with other parents in the hospital, that parents gradually learned that they had certain rights, that it was okay to say "No," and that the medical team could not be fully trusted. They also were reassured to meet real people that were surviving and coping with the calamity of having a child with cancer.

On the other hand, the support group often added to the stress load of the parents. They were distressed to learn that the medical team was fallible, that some children died, that complications could often be worse than the disease, and that money problems were not easily solved. Some of the parents reported the horror they felt at attending the support meeting for the first time. They were confronted with the grief of parents who had lost their children or those whose children had relapsed and were in immanent danger of dying. This illustrates Walker's (1985) premise that the coping efforts of some can increase the stress of others.

Parents of children who were newly diagnosed did not want to see evidences that their child might die. They wanted to believe that everything would be alright. Many of the parents refrained from attending subsequent support group meetings for this reason. They turned, instead, to informal relationships with other parents whose children were at the same stage of treatment. These relationships were easily formed because of the constant contact with other families at the out-patient clinic each week and at the hospital during admissions.

Baldness

The issue of hair loss was largely ignored in the literature. It was included in this study to explore how baldness affects both the children and their parents.

Children

Children remembered the experience of baldness as being difficult at first. However, after the initial shock, lack of hair was a way of gaining attention and special privileges. Most children who were interviewed lost their hair four or five times before treatment was completed. The onset of baldness was usually heralded by a sore scalp, and then within a few days the child was completely bald. Hair came out in large clumps all over the bed, the bathtub, the table at mealtimes, and all over the child's clothing during the day.

Of the 9 children interviewed, only 2 were spared from total baldness. One child lost all but a few strands of hair, and the other child never lost any hair. Catie, the child who never lost any hair, was mentioned by a couple of parents of children who had experienced complete baldness. They expressed feelings of anger toward Catie because she never became bald. None of the children, however, ever voiced feelings of anger toward Catie.

I remember thinking, it's not fair. Catie never lost her hair. She never did. And I thought, well what's so different. She had leukemia, just like Renee, but she never had to go through what Renee went through. I remember being so angry about that. I thought it just wasn't fair. (Renee's mother)

In speaking of their experiences with baldness, the children spoke of the teasing and questions they endured from school friends and classmates when they returned to

school, with no hair, for the first time. However, some enjoyed the special attention they received because of their baldness.

A lot of people made fun of me at first, but I didn't think nothing of it. I had to wear a hat to school, and nobody was allowed to. Pretty soon, everybody started wearing hats, and the teacher had to yell at them. I was the only one who could do it. (Andy)

Parents reported:

She really didn't seem to mind, once we got over getting the wig and stuff. They would play games while we were riding. She would pull off her wig, and look at the car next to us to see what they say. Sometimes she would put her wig on her brother, and that type of stuff. (Molly's mother)

He would take off his hat in front of people, and say, 'Wanna see my Ma kiss my head? Ma, kiss my head!' and I'd kiss it, and it was like, 'Andy, knock it off.' But we'd be in the grocery store, and he'd have his cap on. He had a whole collection of baseball caps we had bought him. And he would always wear a cap when we went out. He was self-conscious of it, but yet he also wanted approval. We would be standing in the checkout line with total strangers, and he would take off his hat. And he'd be just looking at the checkout girl to see her reaction. (Andy's mother)

Some of the children showed a great deal of playfulness in their strategies to cope with the embarrassment of being bald. One child was encouraged by his parents to have his head shaved because his hair was falling out all over the house. He told them that he would have his head shaved, if his dad did, too. So, both father and son went to the barber and had their heads shaved.

Me and him both went to the hair place, because my hair was falling off all over the place. So we said, 'What the heck. It's all gonna fall out,' so we just shaved

it all off. Both of us! But dad said he wouldn't do it again. Only once, 'cause I got bald about 5 times. (Andy)

Another child selected pink and purple "punk" wigs to hide her bald head.

Some of her wigs were pretty outrageous. She had some punk wigs. I mean, you know, we'd go out in public, and she'd wear her purple mohawk, and everyone would stare. But if she had walked in the mall bald headed people would have stared too, so, to her, it was more acceptable to be stared at for being this cool purple headed kid." (Renee's mother)

Parents

Parents responded to their child's baldness in a much different way than the children. Most of the parents made statements such as, "The baldness was much harder on me than my child." When these feelings were explored, during the data analysis, two major themes emerged.

First, the loss of hair made the child appear very ill, and it was something that was evident to everyone who saw the child. Routine trips to the grocery store, post office, and church proclaimed to all that child was very sick. There were stares, questions, and many awkward moments. The baldness brought the parents face to face with the reality that their child had cancer, a potentially fatal disease, and they could not control the outcome. This was very difficult for them, especially the first time.

At first, when I went in that morning, I remember seeing hair all over the floor. I went out of the room and got to crying, and then I got myself together, and went in there, and woke him up, and explained it to him before he saw what was going on. I didn't let him see my crying. (D.J's mother)

It was a constant reminder of what was going on, that you have no control over it. And there was the hygienic part of it, too. It's gotta be cleaned up so she's not laying in it. That was more of a reminder too. (Brenda's mother)

Second, the parents felt very protective of their bald children. Most of the parents expressed concern about the possibility of the child having to endure the teasing and stares of their schoolmates, when they had already been through so much torment with the hospitalizations and chemotherapy treatments. Yet, they had to send the children to school alone. They could not follow them around all day to protect them.

I don't know that it bothered him as much as it bothered me. After all he'd been through, the last thing I wanted was someone teasing him about being bald. I didn't want anyone saying a word about it. But when he got to kindergarten, the kids would look at him and stare, and point and laugh. I was standing in the hallway one day, waiting to pick him up, and I saw these kids down the hall pointing to him and laughing. It just made me so mad. I thought, after all he's been through. (Andy's mother)

It was harder for me than for her, because I knew what she was going through each time. Her hair would just start to grow back, and it would be an inch long, and she'd go get the curling iron, it was really pitiful. Then it would all fall out again. I worried about what it was doing to her self-esteem, because she felt ugly, and she's really such a cute little girl. It was really hard for me to sit back and just watch it. But you can't go out there and beat up all the little playmates and make them shut up. You just have to let her get hard to it. And she did, after a while. (Renee's mother)

Institution

The nurse practitioner at the medical center assisted the children in dealing with their hair loss by making referrals to the hospital educator. This woman was responsible for helping the children keep up with their school work during lengthy hospitalizations,

as their health permitted. She also served as a liaison with the child's regular school, contacting the teacher and principal of the child's school prior to the child's return, to alert them about the child's hair loss.

Schools were given instructions about how to talk to the children in the classroom about the sick child's appearance. Consequently, most of the classmates were prepared for the arrival of the bald child. However, the children on the playground and in the community were not prepared, and they were often the source of much teasing.

The institution also gave anticipatory guidance to the families. During the child's first hospitalization for chemotherapy, the children and their parents were told of the probability of baldness as a side effect of the drugs. They were encouraged to secure wigs or caps for the children before the hair fell out. Expecting the baldness and preparing before it occurred helped both the children and their parents.

Many children abandoned the wigs and caps during subsequent bouts of baldness because they were heavy and hot, and schoolmates seemed less likely to tease when nothing was "hidden." Playmates seemed to respond more favorably to a child with a naked head than to one who tried to hide the baldness with a wig or cap.

None of the children ever wore their wigs or caps to the hospital or clinic. There the bald head was the norm, and the children were accepted as they were. There was no need to hide the baldness. It was, in fact, a badge of membership.

Community

The American Cancer Society provided free wigs to the families. Children were invited to select whatever style and color they wished. Most of the children seemed to enjoy this shopping experience.

Camp Fantastic provided another sanctuary where baldness was completely acceptable, and wigs were not necessary. The children who attended the summer camp and 4 retreat weekends during the year were free to abandon caps and wigs, without fear of teasing or rejection.

Fear of Death

Children

The children were given an opportunity to talk about death twice during the interview. First, they were read the account of the child in the book who noticed that some of her friends at the clinic were dying. The child being interviewed was asked to speculate about how the child in the book felt and what she did about her feelings. Each of the children was asked if they had ever felt like the child in the story and what they had done about their feelings. All but one of the children admitted to worrying about death. The child who stated that he never worried about dying, was the son of the woman who was fiercely optimistic.

Secondly, the children being interviewed were asked to dictate an ending for the story in the book. All the children made the story end with the child growing up and

living happily ever after. None of the children predicted that the child in the story would die, not even the child who was, in fact, dying at the time of the interview.

All but one of the children stated that they had thought a great deal about their own deaths. They said that the child in the story, who worried about death, should talk to her parents about her feelings. However, only half of the children interviewed said that they had actually talked to their parents about their own fears of death. Those who did talk to their parents about death, did so in off-hand remarks. None of the families described in-depth discussions about death between the parents and children.

When asked why they were unable to talk to their parents about death, even though they said that the child in the story should have, the children gave various reasons. One of the girls feared that if she talked about death, she might die.

Well one of the reasons (that kids don't want to talk about death) is that they don't really want to face it. With, like, talking about it, they might think that it'll happen. (Renee)

Others expressed concern that their families would not be able to handle the discussion without crying and becoming distraught. Also, the children themselves feared becoming emotional in front of their parents.

Well, if you think you're going to die, sometimes it helps to talk about it, like talk about how it would be better, because, well I feel like a lot of my family, they weren't doing anything for themselves. It was like, 'my world is Renee', but I could never tell them that, because they would say it wasn't true, and get all upset. (Renee)

I think my mom and dad think I've brought it all out. They don't know that there are some things inside me that are still in there, and that I still haven't let out, that I want to let out, but I just don't have the courage to let out. Because, it's like, if I let it out, they're gonna think I'm getting too emotional. I sort of feel it's, in a way, embarrassing, but I'm not really sure. I mean I never really tried it for sure. (Brenda)

When asked to describe their feelings about death, children said they worried most about dying when friends they had known from the hospital or clinic died. Most of them took comfort in believing that the child who had died just "had a worse case of it" or "had a different kind" of cancer, but two children discussed their fears about death. Renee worried about how she would die.

I had a lot of thoughts run through my mind. I just wondered if I'm gonna die with someone in the room? How many ways are there to die? Will I do it recently, or will I do it long and painful?

Brenda wondered what would happen to her after death.

It's like, if I relapse, and it ends up that I do die. If that happens, how is God going to take care of me? Is it gonna be like everyone says that God is gonna take care of me? You know, if you die, blah-blah-blah-blah. It's like, what happens if that doesn't happen? Nobody has been up to heaven and come back. Everybody would have to go up to heaven and then come back to know it happened. But you know, nobody's really gone up there and come back and said, 'this is what happened.'

Dealing with the death of friends is a constant burden for children with cancer. Few healthy children have to deal with the death of a peer during their childhood years, but children with cancer may suffer through the death of several close friends during their years of treatment.

The sample for this study represents one cohort of families. As the cohort works through the process of dealing with cancer, they grow and learn to cope. They help each other through the ordeal of death. Each death brings fresh realization that their own family may be the next to grieve.

The children handled the death of contemporaries in various ways. One child chose to deny that she was aware of the death of her friend, even though her parents told her of the death.

There was one little girl in particular that was very difficult. They were in a room together, and had the same disease, and she died about a month later. I told Molly about it, and we talked. She asked where she was. We're Christians, so I told her that she was in Heaven, and that seemed to satisfy her. I thought she would be really upset because she did become close friends with this little girl. Once a week we'd take her gifts, and go visit her and that kind of thing. But she never got real upset. (Molly's mother)

Did any of your friends from the hospital die? (Interviewer)

I never knew any kids that died. (Molly)

Your mom said that you were in a room with a little girl one time that had the same thing as you, and then she died later on. Do you remember that?
(Interviewer)

I'm not sure. I had a little girl in the room, but I'm not sure. I don't remember her dying. (Molly)

So, none of the kids that you have known have died? (Interviewer)

Not that I know of. (Molly)

Another child responded to the death of friends by becoming quiet and depressed.

Every time another kid dies she gets depressed. She cries. She can't go to sleep. When we know that she's going through a low, she's not very good at opening up. She just wants to be held. She gets real quiet and wants you to hold her. She starts making bad grades at school and has concentration problems. (Catie's father)

Two of the children felt that saying "goodbye" to the dying friend was very important. Unfortunately, they were not allowed an opportunity to do so. Parents were understandably reluctant to take their chronically ill children to the bedside of another child who was dying of the same disease. They probably reasoned that they were shielding the children from needless agony. The children, however, felt cheated and angry about not being allowed to say goodbye. In these cases, the children had vowed to each other that they would say goodbye before dying, but lack of control and transportation made it impossible to carry out their plan.

We were both close to each other, and we both knew that if we were going to die, we would come to each other and say goodbye. But I never got a chance to say goodbye. At the funeral everyone thought I did fine, but I didn't do fine at all. I felt like I was going to die, because somebody died without me. My friend died and there's no way to get him back so I could just say one little, miserable, goodbye. I thought goodbye to him at the funeral, but I don't really think that anyone knew that I thought goodbye. Nobody knew how I felt, and I got really disappointed because nobody knew, nobody wanted to know. And it really scared me that I was going to die too after that, but it's been a year. (Brenda)

He felt cheated when Jake died. He felt like Jake left and never said goodbye to him. He even said that the night of the viewing. We took him to the viewing. We never intended doing it, but he insisted. He said, 'I have to say goodbye, I want to see him one more time.' So, when he got there, he walked up to the casket, stood there for a little while, and then said, 'Okay, let's go.' It was like he saw it, and it was real, and he said goodbye, and then he was done. (Andy's parents)

Parents

Parents feared the death of their children most during the diagnosis and completion phases. They reported that they were less fearful during the treatment phase because the children were in remission and healthy at that time. However, the threat of relapse was a constant concern, and if the child relapsed, fear of death became a major stressor.

Parents handled death fears in different ways. Loss of control seemed to be the prevailing emotion, and each family sought to regain a sense of control in some way. All of the parents, except Camden's, fit into one of three groups, summarized in Table 2. Camden's parents seemed to display characteristics of two of the groups.

Table 2. Ways parents handled loss of control in regard to fear for their child's death.

Group	N	Ways of Coping
Controllors	2	Trusted in themselves to control the child's medical care and disease outcome by learning about the disease and it's treatment. Tended to "fight the system" at the medical center.
Believers	4	Trusted in God, fate, or the power of positive thinking to control the child's care and the outcome of the illness. Were less critical of the staff at the medical center.
Followers	3	Trusted in the medical staff to control the child's care and the outcome of the cancer. Were reluctant to interfere with staff routines.
Mixed	1	Alternated between being taking control into their own hands and trusting the medical staff completely.
Total	10	

Two of the parents (Controllors) coped with their fears of the death by taking control for the child's treatment into their own hands. They seemed to believe that their own interventions would determine whether the child lived or died. They learned everything they could about the child's disease and took responsibility for the child's care by watching each procedure, supervising each medication administration, and asking endless questions. The parents in this group did not trust the medical staff and were frequently critical of the care their children received. They fought the system at the

hospital by challenging the doctors and nurses when they believed that optimal care was not being delivered.

If she wasn't happy about the answers she was getting, I would find out. I didn't care who it was or what I had to do to get the answer. I was gonna get the answer. And, I didn't let anybody dodge me with their B.S. Okay, tell me the facts, just the facts, and that's all I wanted to know. That was the position I took through it all and probably still take that position. (Andy's father)

Brenda's parents took her to physicians outside the medical center when they believed she was not receiving appropriate care:

The blood work came back, and her liver enzymes were over 1,000. He (a physician outside the medical center) said, 'She's just reacting to all the methytrexate'. So he called the medical center and told them the results and told them that he recommended that she be taken off the medication until the counts came down. Well, the medical center never called back for the 3 full weeks until our next visit. Of course, by then, we'd taken her off the medicine, had her rechecked 3 more times and got her back on the medicine again. So we got to the clinic at the medical center and the 2 doctors called us into their offices, and literally read us the riot act, and they said they didn't want us going to other doctors for other opinions. They said, 'Don't go to Dr. L, and don't go to your family doctor, you come to us for everything.' And we said, we called you, and you didn't want to do anything. They were furious about it. You feel so emotionally blackmailed by them. (Brenda's mother)

A second group of parents (Believers) sought control by trusting in God, fate, or the power of positive thinking. Some placed their children's name on nationwide prayer lists and trusted God to either cure the child of the cancer or use the ordeal for some higher purpose.

My first reaction was, 'Why D.J.?'. Then I stayed so heavily burdened and laid in bed at night, and it was always on my mind. Then it was just like one day, you know, I thought, 'Don't question why.' and since that day, I just let go. I don't

question God anymore, because I feel like it was God's will that he did it, and it was done for a reason. He could have taken him, but he choose not to, and he left him here. We just have to do the best we can, day by day, because life is not guaranteed to anyone. If he was taken today, then we could say that he was here, and we made him happy. (D.J.'s mother)

When they said that there was nothing more they could do, because the medicines weren't working, I came home, and I got on the telephone, and I started calling prayer chains. I told them exactly what the doctor told me, and I didn't cry or anything, because it didn't seem real. The next morning mama called, and said that Catie's temp had broke, and the chemo was working. Just like that. When the doctor came in that morning, I told him that the Lord had done it, and he said that he believed in being realistic. But, I was grinning, and I said, 'Well, that's about as realistic as you can get!' (Catie's mother)

I felt like I was given strength when I needed it. I felt real secure. People were praying for Catie. I felt like everything was out of my control, and I didn't feel weighted down. I just felt calm. (Catie's father)

Brad's mother believed that he would not die, because she was thinking positively:

We all thought positive, and we all concentrated on him that he was going to make it. But, if one of us stumbled and fell, that was going to hamper his getting better. I read Why Bad Things Happen to Good People and The Power of Positive Thinking. I read everything I could get my hands on about positive thinking. When they said to me that I had to face reality, I said, 'I am facing reality. My child is going to get better.' (Brad's mother)

This group of parents were less critical of the medical center staff, because they believed that their child's future was ultimately controlled by God or fate. Therefore, there was little need to fight the earthly system.

A third group of parents, the "Followers", placed their trust in the medical staff. They believed that the best way to assure the recovery of their children was to follow the

physician's instructions. Although all the parents had access to the same information, these parents seemed to prefer to "let the experts make the decisions."

They brought in a thing explaining the treatment and everything. I found out that at one stage they would give a lot of medicines, and then if they were able to get them in remission, they would be placed in the A, B, C, or D protocol. This was all new to me, and I was frightened for her to take it, but, you know, I didn't have any choice in the matter. (Lisa's mother)

In reality, according to the nurse practitioner, all parents were given choices about the protocols. They were asked to decide whether they wanted to select a particular protocol for their child or have a computer place them randomly in a group. Lisa's mother seemed to believe that she had "no choice," because it was best to let the physician choose for her.

Institution

Personnel at the medical center dealt with the fear of death indirectly, by attempting to provide the best possible medical care and maintaining an atmosphere of openness and honesty. Parents and children were given much information about cancer and its treatment. They are given choices about treatment protocols and supported by visits from the nurse practitioner.

Usually the child is admitted to the hospital, and then I'll meet them and explain my role, and I take them some information to read. We try to be real open with the children and parents. We discourage the families from shielding the children from hearing their diagnoses, even if it is something they don't really understand. (Nurse Practitioner)

I've had 10 year olds say to me, 'Well, if I stop taking the chemotherapy, how long will it take me to die?' and I try to be as honest as I can. I say, 'I don't know how long it would take. Some kids will die in a short time, and some people will go on for quite a long time with no chemotherapy.' I never tell them that they will die in 3 days or whatever. If a kid asks if he is going to die, I would tell him that we don't know, but we do know that the medicines aren't working anymore. That way you tell the truth, but you don't take away all hope. (Nurse practitioner)

Community

Camp Fantastic had no real program for assisting children in dealing with the death. According to the camp director, the whole purpose of the camp was to promote feelings of normalcy among the pediatric cancer patient campers. Therefore, no time was given to counseling children in how to cope with the illness or the death of friends. Campers were kept busy, accepted completely regardless of their physical state, and encouraged to forget about their cancer for one week.

In spite of these precautions, the awareness of death was always present during the first few days of camp. Children who looked forward to seeing old friends, and absences brought inevitable questions. The Camp Director reported that he answered questions honestly, but did not want the children to spend camp time dwelling on lost friends. Camp leaders have been discussing a change for next year that will honor the children who have died and give a feeling of closure to those that are left behind.

One of the problems is that if the child finds out about the other child's death when they arrive at camp, it could potentially ruin their whole week. But of course, you have to ask yourself, 'Is it more important that they know or that you hide it from them so that they can enjoy camp?' I think what we're going to

do this year (that we have never done before) is to have a memorial service that doesn't necessarily pertain only to people who passed away. In other words, we will start out camp and say, 'We want to take a moment to remember or think of anyone who's not with us in camp.' Could be parents, grandparents, the friend next door, anyone they wish could be here, but isn't. Then we want them to think about that person, and basically remember them as they do things at camp. We've never done anything like this before, because obviously we don't need to go through an obituary at camp. But these kids know that a lot of kids have died, and they need help resolving it. It's good to do something in terms of letting the kids know they'll be remembered, then at least they'll have the peace of mind of knowing that, if they don't come back, people will remember. (Camp Director)

The children placed an enormous amount of importance on going to camp. Camden was hospitalized and near death when camp began last summer. He pleaded with doctors to give him "enough medicine to make it to camp". He was able to attend the last three days of camp, and although he was unable to do much because of his weakness, he reported that he had a wonderful time. One would have to wonder if his last trip to camp took on added importance because he needed to say "goodbye" to his friends and counselors.

The Candlelighter's Support Group and the American Cancer Society both assisted children and their parents in dealing with the fear of death by providing forums from which they could ventilate feelings and accept the support of others.

Candlelighters sponsored monthly meetings at the medical center, and the American Cancer Society hosted retreats for the families.

Actual Death and Keeping the Memory Alive

Children

Two of the children in the sample did die. Alex died about one year prior to the interviews, so his mother told his story. Camden died shortly after his interview. I had the privilege of caring for him and his family, as a nurse, during the weeks preceding his death, and I spoke at his funeral after he died.

Neither of the children who died talked to their families about death other than in off-hand comments or non-verbal expressions. However, when they were in the act of dying, it was the children who informed their parents that death was imminent. Alex's mother reported, in her interview, that Alex's attitude about treatment changed after his second relapse. He no longer cooperated, and he questioned why chemotherapy was necessary, since it was not working. He seemed to give up his will to live and became withdrawn and short tempered.

In the days prior to his death, he played video games and watched television, but did not want to talk or be touched. Six hours before his death, he informed his mother that he was dying. The following quote tells the story from the mother's point of view:

He wasn't resting well, but he didn't want to talk, he didn't want me to read to him, and he especially didn't want to be touched. He wasn't able to concentrate on much. He was just kind of laying there, sighing a little sometimes. I sat with him until about midnight, and then I laid down on the little cot near his bed. About one o'clock, he said, 'Mom! I've gotta throw up!' I jumped up, and I could tell, even though it was dark, that he was throwing up blood. I called the nurses and said, 'Alex is throwing up blood, and I've got to have some help.'

They came in, and by then I was laying on the floor, because I felt like I was going to pass out, but I said, 'Don't worry about me. Just take care of him.' So, they got him cleaned up, and they left the room. Well, he looked over at me and said, 'It's all over.' That's what he said. I called his father and said, 'Get down here right away.' and he came. Alex died about seven in the morning" (Alex's mother)

So, were you aware at that time, that he was in the act of dying? (Interviewer)

When he said, 'It's all over', there was no question about what it meant, but up until he said it, I didn't know. I knew it was coming, but not that it was happening right then, that night. (Alex's mother)

Camden was admitted to the hospital about 3 weeks prior to his death with a high fever, pneumonia, and a bone infection which he was unable to fight because his immune system had been damaged by the chemotherapy. Essentially, medical science had nothing more to offer him, and he was not expected to live through the night. However, Camden did live. He managed to hang on to life for three more weeks, until he was sure that his parents had accepted his death and given him permission to die. I will tell the story of his last days and his death from my own observations, made while I cared for him and visited him during my hours off from work.

In the weeks leading up to his last admission, it was clear that Camden's parents were in a state of denial about the possibility of his death, even though, medically, it was certain that he was dying. He had entered into his second relapse, and chemotherapy was unable to initiate remission. He was not a suitable candidate for a bone marrow transplant, because he was unable to attain remission.

About a month prior to his admission to the hospital, Camden had tried to discuss the topic of his death with his parents by using an off-hand comment while riding with his mother in the car. His mother describes the conversation:

He was talking and he said, 'Mama, when I die, are you going to have a funeral for me?' Just like that, in the car coming home. I said, 'Well, Camden, you're not going to die.' And he said, 'Well, Mama, are you going to have a funeral?' and I told him that everybody usually has a funeral. But it blew me away.
(Camden's mother)

When the parents were interviewed, about a week later, they were very upset because they had just been told by the physician at the medical center, that Camden would die within 6 months. Although they had already told me about the comments Camden had made about his death, they denied that he had any knowledge of his terminal condition. They also refused to believe, for themselves, that he was dying.

How has Camden reacted to the news that he is dying? (Interviewer)

Camden doesn't even know it. (Camden's mother)

Because we're not satisfied that it is true. (Camden's father)

When I interviewed Camden the next day, I told him that the little boy in the story was worried about dying, and asked him to tell me what the little boy should do. Camden folded his arms across his chest, looked out the window and said, "He should forget about it." Clearly, Camden seemed to have concluded that the adults in his world were not ready to discuss his death, so he was keeping his thoughts and fears to himself.

About a week before his death, Camden's parents finally admitted that he was dying, but Camden continued to hold on to life, against all odds. His parents voiced concern that Camden was clinging to life and grieved about the suffering he was enduring. I advised them to verbally give Camden permission to die, and they did.

However, along with acceptance of death came planning the funeral.

Unfortunately, Camden's parents and grandparents could not agree about how the funeral should be conducted. They sat around his bed arguing about who's pastor should speak and the general format of the service. They believed that Camden could not hear them, because he was heavily sedated with morphine for pain. If Camden was aware of the discord, he may have continued to live until it was settled.

A few days later, he seemed more comfortable than he had been in several days. He spent the day kissing the nurses "Good-bye" and having his picture taken with them. That afternoon he called his mother at work and told her to come right away. When she told him that she would come about 7 pm, he replied that he could not wait that long. He also requested that his pastor come to see him. That evening he talked to the pastor about life after death, told his parents he was leaving, and quietly died.

Camden's story vividly portrays the role reversal that Bluebond-Langner (1978) described in her work with dying children. In death, Camden became the caretaker of his parents. He concealed knowledge of his death from them when they were not able to

accept the fact that he was dying. He even seemed to postpone his death, in spite of tremendous suffering, until they were able to accept it, and family disputes were settled.

Parents

In families that lost a child to cancer, parents were quite concerned about keeping the child's memory alive after death. They sought comfort in feeling that the death had served a purpose. Alex's mother was interviewed about a year after his death. She had given his favorite bike to a little girl who had been his playmate and was distressed that the child was not using the bike, but saving it as a treasure.

I ran into Elizabeth's mother recently, and I hoped that, I mean, I had told her that I really wanted Elizabeth to get out and run the tires off that bike, and really use it. I asked her mother about it, and she said, 'Well, it's sort of a treasure.' It's sort of one of those, it might get rained on. Get it inside the garage, it might get dirty. Which is really not what I wanted. I mean, it's a good bike, and it ought to be used. I gave it to her in part because I wanted her to have it, and in part because the only other way I could see getting rid of it was to sell it, and I didn't want anybody dickering with me on the price of it. (Alex's mother)

I went to a meeting of Compassionate Friends, and it was really good. They were talking about the "forgotten child" and how once a child is gone, it's hard for their memory to be maintained. That's why, you know, my family and I are furnishing a room down at the Ronald McDonald House in his memory. And I've also donated a few books to the library in his memory. (Alex's mother)

Camden's parents were not interviewed after his death, but within a month of his death, they donated a memorial to the pediatric floor at the hospital. It was a beautifully framed poster about nursing which contained an inset of Camden's obituary in the bottom left hand corner. Along with it were a framed lithograph of the poem that

was read at his funeral and a picture of Camden that was taken at the hospital a few days before his death. These items now hang on the wall opposite the nurses station, where all who enter the unit will see them. They pay quiet tribute to a little boy who lived and died there.

CHAPTER FIVE

DISCUSSION AND CONCLUSIONS

Overview

In this study, I investigated the thoughts, feelings, and actions of children with cancer. Contextual layers were also explored to gain a complete picture of how children's coping responses were influenced by adults in the home, institution, and community. The questions that guided the research were:

- 1) What are the children's thoughts and feelings regarding their illness?
- 2) How do they cope with the ramifications of the illness, such as nausea, painful procedures, baldness, and uncertain prognosis?
- 3) What are the home, institution, and community contexts that surround the children as they cope?

Two theoretical frameworks supported this investigation of coping in childhood cancer: Walker's (1985) family stress paradigm and Lazarus' (1984) theory of stress and coping.

Findings of this study were based on data collected from interviews with 10 families of children with cancer. All but two of the children had completed treatment for cancer and remained in remission at the time of the interviews. One child had relapsed and was in the hospital when he was interviewed. Another child had died about 1 year prior to this research, but his family was interviewed to relate the story of his illness and his death. Representatives from the institution that delivered the

children's medical care, and community agencies that offered support to the families were also interviewed.

The purpose of this chapter is to discuss the research findings in light of the theoretical models, the research questions, and the literature review. First, integration of the findings related to the conceptual frameworks will be discussed. Next, findings relative to each of the research questions will be presented as related to the literature review.

Discussion of Findings

Theoretical Integration

The Walker (1985) and Lazarus (1984) models provided lenses for viewing the stress and coping of pediatric cancer patients and their families. The contribution of both models allowed the construction of a complete representation of the factors influencing the thoughts, feelings, and actions of the individuals in this study.

Walker's Family Stress Model. Walker (1985) emphasized interdependent relationships within families, and between families and outside systems. According to Walker (1985), individuals differ in their response to stress, and the coping efforts of some may potentiate the stress of others within the group. This study provided ample evidence to support Walker's conceptualizations.

Husbands and wives reacted differently to the stress of having a child with cancer, and each tended to resent the coping efforts of the other. Mothers tended to

focus entirely on the care of the sick child. Fathers tended to worry about remaining in control, keeping the family together, and taking care of financial worries.

Consequently, mothers believed that their husbands were not taking the child's disease seriously, and fathers perceived that their wives were over-reacting.

The need of mothers to stay with sick children and the compulsion of fathers to work and make money to alleviate financial concerns, further eroded marital relationships by making communication difficult. Mothers were consistently involved in care of the sick child, and fathers were often at work leaving little time for discussion and resolution of problems.

Children enjoyed the attention they gained by being sick, but felt guilty about the problems they caused in the home. Siblings felt neglected and isolated because they were often shuffled from one house to another while parents were occupied at the hospital and at work. When the sick children arrived home from the hospital, siblings continued to feel left out, because attention and gifts were heaped upon the sick child. Siblings tended to become angry and jealous, increasing feelings of guilt in the sick children and contributing to the stress of the parents.

Mothers were sensitive to the emotional needs of the well siblings, but felt unable to invest time in anyone other than the sick child. Therefore, they catered to the needs of the child with cancer, but they felt guilty about neglecting the other children.

Parents demonstrated diversity in their responses to the services of the medical staff at the institution. Some parents valued the judgment of the staff and trusted them to deliver appropriate care to their children. Others took the responsibility for their child's care into their own hands and watched warily over the care administered by the staff. A third group of parents placed their faith in God, fate, or the power of positive thinking to control the outcome of their children's illness.

Some parents gained emotional support by attending the meetings of the Candlelighter's groups, while others reported that the meetings actually added to their stress, because they saw other parents grieving the relapse or death of their children. A few parents found comfort in the sessions, but most were frightened by the meetings. They had no desire to know the possible complications that awaited them.

Lazarus' Model of Stress and Coping. Lazarus (1984) emphasized the dynamic unfolding of the stress response, noting that individual reaction to stress changes over time. He viewed cognitive appraisal as the basis of all coping. Findings of this study provide many examples that support Lazarus' (1984) ideas. The stress responses varied greatly in the three phases of cancer treatment. Both parents and children gradually changed their thoughts, feelings, and actions as time went on, and even children were capable of cognitively appraising stressors.

Children were fearful and combative during the diagnosis phase, but they learned to cooperate with most procedures by the time they completed two or three years of

treatment. They never became accustomed to lumbar punctures and bone marrow aspirations. The fact that these procedures were far more painful than the others, demonstrates that the children were able to make accurate threat appraisals and act on them.

Children initially resisted staff members and treated them like enemies. Later in the illness process, they realized that staff members meant them no harm, and many developed enjoyable friendships with them.

During the diagnosis and treatment phases children were open in telling adults about their cancer, but concealed the fact from peers. Through cognitive appraisal, they learned that adults reacted to the news with sympathy and gifts, while peers tended to alienate the sick children. After treatment was finished and children missed the special status they had experienced while they were ill, they began to share openly with classmates about their cancer history.

Children in this study feared death and worried frequently that they would die, but most never discussed their fears with their parents because they perceived that the parents were unable to accept the possibility of death. The children did not want to see parents break down emotionally, so they resisted speaking about death except in off-hand comments which "tested the waters." They did talk to other children about dying and secretly made plans to meet and say goodbye before death occurred.

Parents showed distinct changes in their coping patterns during the illness process, as well. Initially, they reported being in a state of shock. They felt numb and were unable to make decisions. A few days later, they began dealing with the crisis at hand.

Parental attitudes toward the medical staff changed over time from trust, to wariness, to feelings of dependency. Feelings about chemotherapy also changed. Initially, many parents feared the drugs because of the harmful side effects. Later, parents placed great faith in the power of the drugs to initiate and maintain remission. By the time the children completed treatment, the parents felt dependent on the drugs and feared their withdrawal.

One mother changed drastically in her coping responses. She was fiercely optimistic during the diagnosis and treatment of her son's cancer, believing that the power of positive thinking would keep him alive. After his treatment was completed, and he was pronounced free of cancer, she suffered a year of clinical depression.

Parents feared the death of their child during the first few weeks after diagnosis, but then reappraised the situation and felt less fearful when the child was safely in remission. After treatment was finished, and chemotherapy was withdrawn, fears of death re-emerged. Parents feared their children would relapse when the drugs were withdrawn. Camden's parents were unable to accept the fact that he was dying until a

week before he passed away. Then they gave him permission to die and concerned themselves with selecting an appropriate memorial to keep his memory alive.

Families enjoyed ample support from friends, neighbors, co-workers, and church groups during the initial weeks of their ordeal with cancer, but the support waned once the child was in remission. People outside the family tended to assume that support was no longer needed once the child was out of imminent danger. Diminished support increased the stress of parents, and some developed feelings of anger and resentment.

Implications of theoretical insights. Based on this study, it is apparent that pediatric cancer patients and their families are affected by contextual factors. All family members are affected by their experiences with the illness process, and a variety of coping responses are displayed. The coping efforts of some profoundly affect the stress levels of others. Children and parents alike are capable of making appraisals and reappraisals based on cognitive scanning of available resources and changes within the environment.

Children can learn to cooperate with most painful procedures, but some are so painful that adjustment is unlikely, and children need sedation or other support to be able to tolerate them. Medical staff members can be valuable facilitators in assisting children in coping with sickness and hospitalization.

Siblings of pediatric cancer patients need consistent adult attention to prevent extreme feelings of isolation and jealousy. Special activities such as Top Brass Camp

(for siblings only) provide innovative ways for valuing these children and contributing to their emotional well-being.

Families of children with cancer need assistance in communicating with one another and appreciating individual coping styles. Retreats such as those offered by the American Cancer Society could serve as useful interventions in this area.

Parents often display inconsistent attitudes towards the medical staff and the value of treatment protocols. Allowing parents to assume whatever measure of control best suits their coping style could relieve anxiety and promote more appreciative relationships between parents and staff. Community agencies need to concentrate services for the families of pediatric cancer patients during the treatment and diagnosis phases to compensate for the diminished support offered by family, friends, and co-workers.

The Illness Process

Each of the topics included in the three research questions will be discussed in light of the findings and the literature review. The first research question dealt with exploring the way children understood their illness. The data were examined to form a clear picture of the children's thoughts on contagion, immanent justice, understanding of death, and feelings of isolation in the hospital.

Young children often extend their definition of contagion to include non-transmissible diseases as well as accidents (Bibace & Walsh, 1981; Kister & Patterson,

1980; and Perrin & Gerrity, 1981). The children interviewed for this study were in kindergarten or first grade at the time of their diagnosis, and they were sometimes isolated socially due to classmate's fear of "catching cancer." However, none of the children with cancer believed that they had "caught" the disease from someone else.

The question of whether or not children believe that they become sick because God is punishing them for something they have done is one that has been frequently discussed in the literature (Kister & Patterson, 1980). All of the children in this study were concerned about discovering the origin of their cancer. At the time of the interviews, the children were 8 - 11 years old. They no longer believed that their diseases were a punishment for some bad deed, but almost all of the children admitted to that perception during the first weeks after being diagnosed. The type of misbehaviors for which they thought they were being punished were usually quite trivial.

Clunies-Ross and Lansdown (1988) found that children with leukemia were more likely than other children their age to understand the irreversibility of death and the cessation of bodily functions. The children in this study demonstrated a clear understanding of death. Most of them had experienced the death of close friends in their cancer cohort. None of them expected the dead friend to come back or to continue living in some other form, in another place.

They placed a great deal of importance on saying good-bye to dying friends because they understood that they would never see them again in this life. Some of the

children believed that they would know when they were dying and promised each other that they would say good-bye. However, the dying child was rarely able to keep these promises, and the surviving children grieved over the fact that they were unable to say good-bye.

Although the children seemed to have a clear understanding of death, few personalized it to include a realistic view of the possibility of their own death. All of the children, except Brad, admitted to worrying about death, especially when other children died from the same disease. However, most of them comforted themselves by believing that the child who died "had a worse case" or "a different kind" of cancer.

Clunies-Ross and Lansdown (1988) asked young cancer patients to draw pictures of themselves in the hospital. The children tended to draw themselves alone, with sad faces, demonstrating feelings of isolation. The children in the present study remembered hospitalization in more favorable terms. They enjoyed the attention they received from hospital personnel and visitors, and they described how they had played while admitted to the hospital.

Children in this study were asked to draw pictures of themselves to illustrate the book. Five of them drew themselves in the hospital, but none of them drew themselves alone. All but one of the children drew themselves in play situations in the hospital.

Coping with Specific Stressors

The second research question dealt with the child's ability to cope with the ramifications of cancer diagnosis and treatment. The discussion centered around making accurate threat appraisals, coping with pain, coping with hospitalization, and coping with baldness. The findings of each of these topics will now be discussed.

Scavnicky-Mylant (1987) questioned the ability of young children to make accurate threat appraisals. She found that young children reacted negatively to all medical procedures, but older children were able to differentiate between those that seemed painful and those that were actually painful.

In this study, the children initially reacted negatively to all procedures. However, with experience, they began to make more accurate threat appraisals by cooperating with most procedures, but fighting bone marrow aspirations and lumbar punctures. The latter procedures are more painful than the former, so the children did make appropriate appraisals of the level of threat inherent to each procedure.

Children interviewed before and after bone marrow aspirations to discover the coping strategies they had used (Hamner & Miles, 1985) stated that they were able to cope with painful procedures better when parents accompanied them to the procedure room. The findings of this study concur with Hamner and Miles' (1985) study. All of the children stated that parental presence was an important factor in their ability to cope.

Parents also expressed understanding of the importance of their presence in helping their children cope. Most of the parents accompanied their children to each procedure, and they stayed with them, in the hospital, throughout each admission.

Only one study was found in the literature that dealt with the issue of baldness in pediatric cancer patients. Heffron, Bommelaere, and Masters (1973) conducted a series of support group meetings for parents of children with cancer. They found that the parents reacted more negatively to the children's baldness than the children themselves.

The parents in this study expressed the same feelings. Their inability to change the baldness process increased feelings of loss of control in the parents and caused them to feel very protective towards their children. The young cancer patients in this study remembered baldness as a stressful event, but they also recognized that the baldness afforded them extra attention and special privileges.

The children learned that peers were less likely to tease them if they were open about their baldness. Several of the children choose to forego their wigs and caps after their first episode of baldness, and found that their naked heads caused less of an uproar in the classroom than the wigs and caps.

Contextual Layers

The third research question dealt with the context in which children experienced cancer. The dimensions explored were the family, the institution, and the community. The findings for each contextual layer will now be discussed.

Brett and Davies (1988) described the phases a family went through during their child's diagnosis and treatment for cancer. During the diagnosis phase, they found that the parents felt alarmed and believed that their child's recovery was impossible. During the treatment phase, the parents entered a stage of hope, in which they believed that the child's recovery was possible, but not probable. Finally, during the completion phase, the parents reached a stage of relaxed vigilance, in which they believed that their child would probably recover.

The data for this study partially supported the Brett and Davies (1988) research. Parents did begin the diagnosis phase with alarm and shock. They believed there was no hope for their child's recovery. Next, parents in this study entered a period in which they grew accustomed to the changes that cancer had made in their lives. This stage was similar to the "hope" phase described by Brett and Davies (1988).

The findings of this study reflected a different attitude among parents during the completion stage. The parents I interviewed expressed an increased level of stress and fear of relapse during the completion phase. They feared that the withdrawal of drugs and infrequent clinic visits would precipitate a relapse in their children. Rather than "relaxed vigilance" during the completion phase, there was a definite sense of increased vigilance.

Soccorsi, Lombardi, and Paglia (1987) found that parents of pediatric cancer patients focused their coping efforts on warding off death. Parents refrained from

speaking of the possibility of death for fear that it would occur. Siblings of the sick children understood that the subject of death was taboo, and they took on the role of emotional orphans to allow the parents more time to fight the death of the sick child. Only after the cancer ordeal was over did the families begin to talk about what could have happened and to express the feelings they had repressed during the months of suffering.

The findings of this study support the findings of Soccorsi et al. (1987). Parents tended to concentrate all their efforts toward fighting the disease. The siblings of the sick child were pushed aside, producing feelings of isolation, anger, and jealousy.

The institutional representative that was interviewed for this study was responsible for helping children and their families cope with the diagnosis and treatment of cancer. She assisted the children in coping with painful procedures by using distraction, providing information, and allowing the children as much control as possible. For the parents, she provided information, anticipatory guidance, and referrals to community agencies that provided support.

Three community agencies were represented in this study. The American Cancer Society assisted the families by giving financial assistance for travel to and from the hospital and parking and lodging fees while children were in the hospital. They also provided wigs and sponsored biannual weekend outings for the whole family.

The Candlelighter's Support Group offered support to families of children with cancer. Most of the parents interviewed for this study, spoke negatively about the support given by the group.

Camp Fantastic was a tremendous support for the children. They were able to enjoy a week during the summer when they felt "normal" and accepted. They left behind overprotective parents and enjoyed normal camp activities. Their baldness was no issue because many of the other campers were also bald.

Smith, Gotlieb, Gurwitch, and Blotchy (1987) reported that children gained confidence, and mothers became less overprotective due to the camp experience. These findings were supported by the present study. Children reported feeling much more normal and independent after camp, and mothers remembered that their children returned from camp with more self-sufficiency and confidence.

Limitations of the Study

This research study would have been strengthened by using a format that was longitudinal rather than retrospective. The limitations of retrospective interviews are well known (Lazarus, 1984) including faulty memory, selective memory, and the desire to look favorable to the interviewer. Had the research been conducted over the entire span of diagnosis, treatment and completion phases, other themes may have been evident.

Adding data collection by observation at the clinic and the hospital would also have strengthened this study by adding a triangulation of data sources. Observational data would have corroborated the interview data by demonstrating whether or not the family actually acted and reacted as they recall. Contextual relationships between family members and the institution may also have been more apparent.

Using a larger sample would have given more depth to this study. Since all the families interviewed for this study were drawn from one cohort of families, all experiencing the same stages at approximately the same time, the findings cannot be generalized to the greater population of pediatric cancer patients and their families. Perhaps a larger sample, from a variety of cohorts could have offered more generalized data without destroying the contextual boundaries of this particular medical institution and community.

Suggestions for Further Research

The conclusions of this study present several topics that warrant further investigation. First, marital problems were experienced by many of the parents during the diagnosis phase, when they need to support each other most. Further research needs to investigate supportive programs that would prevent the marital problems or assist parents in working through them more quickly.

Second, children in this study were able to adjust, with time, to most of the painful procedures that were routinely performed on them. However, they were never

able to cooperate with bone marrow aspirations and lumbar punctures. More research on interventions that could be utilized to help the children through these procedures is needed. It is possible that hypnosis, sedation, or some other form of assistance could be given the children during these procedures to make them less traumatic.

Third, siblings suffered emotional isolation and feelings of anger and jealousy because of the attention and gifts that were lavished on the sick child. Further research into means of preventing such emotional trauma to these innocent children needs to be conducted. Perhaps additional interventions such as the Top Brass Camp for siblings could be devised.

Fourth, the completion phase was a time of great stress for parents and the children due to fears of relapse. Further research could investigate what types of programs are possible to assist the parents in feeling more secure about their own abilities to detect relapse symptoms if one should occur and educating parents and children about the probability of survival.

Fifth, the gender issues revealed in this study warrant further investigation. The differing coping styles between the mothers and fathers, and the protective feelings of the mothers are of particular interest.

Sixth, most of the families in this study had negative experiences with the Candlelighter's Support Group. Families of newly diagnosed children did not want to hear about the problems of families whose children had relapsed or died. Changes need

to be made in support groups to provide a positive experience for families of children at all stages of treatment.

Finally, some of the families in this study reported a sense of personal growth due to their experiences during their ordeal with cancer. Future research is needed to discover why some families experienced personal growth and others did not. Factors that lead to personal growth need to be identified so that other families could be assisted in experiencing positive personal changes.

Summary

This study was conducted to explore the experiences of pediatric cancer patients and their families. The findings indicated that children were ambivalent in their attitudes toward the disease process. They did not enjoy painful procedures, sickness, frequent hospitalizations, and baldness, but they did welcome the special attention brought about by these stressors. Children exhibited more of an understanding of affect of their illness on the family than expected. They felt guilty about family hardships which resulted from their illnesses, and they feared relapse and death but often hid their feelings to protect their parents.

Differing ways of coping between mothers and fathers often caused feelings of resentment and marital difficulties. Parental attitudes toward the staff at the medical center varied from trust, to wariness, to dependency. Parents enjoyed the support of family, friends, and community agencies during the diagnosis phase, but waning

community support during the treatment and completion stages caused some parents to feel bitter. A few parents derived a sense of personal growth from their encounter with the illness process. Many expressed a desire to help others who were experiencing the same stressors.

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APPENDIX A

Children's Interview Guide

Warm up questions:

What is your name? How old are you?

Do you have any brothers and sisters? What are their names?

Do you go to school? What grade are you in? Do you like your teacher?

What do you like best about school? Least?

Have you ever been in the hospital? What happened to you?

You have (whatever the child calls his illness)? I am writing a book about a little (boy or girl) your age who had to go to the hospital. But, I was a little girl a long, long time ago. So long I can hardly even remember it...and I was never in the hospital when I was little. So, you know a lot more about being in the hospital than I do. Would you help me write my book?

I have parts of it finished, but I don't know what to write in some of the parts. Those are the parts that I need your help with. I tell you what! If you help me write my book, I'll put your name in my book when it is published..OK? Could you draw some pictures for the book too? OK..we'll do that later. Right now let me read you what I have so far and then you can help me fill in the hard parts. I am so glad you are going to help me!

The Story (The story will be modified to fit the disease and gender of each child so that they can relate to the story.)

Once upon a time there was a girl named Susan who lived with her family in a small town. Susan loved to play outside with her dog...(What should we name the dog?) Sometimes the other kids in the neighborhood would come over to Susan's house and they would all play hide and seek or ride bikes together. They also liked to play nintendo and Susan could beat all the games before any of the other kids.

One day the neighborhood kids came over to play, but Susan did not feel like running or riding her bike that day. She just sat and watched the other children play. A few days later, the children came to play again and Susan's mother told them that Susan could not come out because she was sick. Poor Susan had a fever and he ached all over. She didn't feel like playing or eating or even watching TV.

Susan's father told her that she would feel well in a few days so she just rested and rested and waited to feel better. Her mom brought her ice cream and comic books and even her little brother was nice, so it wasn't too bad being sick for a few days. But a week went by and Susan did not feel better. She was hot and tired and ached all over. Being sick was not fun anymore! Susan's mom was worried because Susan did not get better. She decided that something was very wrong. She made an appointment to take Susan to the doctor the very next day.

The next morning Susan woke up hoping to feel much better, because she did not want to go to the doctor's office. But she didn't feel better, at all. She felt worse. She could hardly get out of bed and get dressed because she was so weak, and besides that, her bones hurt. Mother helped Susan get into the car and let her lay down in the back seat with a big, fluffy pillow.

When they got to the doctor's office.....(Here's the part I don't know. What do you think happened next? Did the doctor hurt Susan? What did the doctor do? Why did the doctor do that?)

Susan had to go to the hospital right away, so that the doctors could make her well. She and her mom stopped at K-Mart on the way to buy new pajamas and coloring books and shiny new crayons. Susan even got to pick out a cuddly, new teddy bear to be her friend while she was in the hospital. Susan noticed that her mother seemed to be crying.....(So, what do you think happened at the hospital? Did hurting things happen? Why was the mother crying? Did any good stuff happen at the hospital?)

When Susan got home from the hospital, she still didn't feel very well, but father told her that the reason she felt sick inside was because the medicine was working. Susan wondered why the medicine made her feel sick. She thought medicines were supposed to make kids feel better, not worse. She asked mom about it and she said.....(What do you think I should put there?)

A few weeks later, Susan was feeling much better. She was able to run and play again and she wasn't tired all the time. She was out in the yard with (the dog) when some friends came over. They said, "Are you feeling OK now?" She said she was, and asked them to play with her. A few minutes later, they were playing hide and seek and Susan found a great place to hide. She was all crouched down under a burlap bag in the back of her father's pick up truck. No one will find me here, she thought. Just then the truck began to wiggle. Susan peeked out from under the burlap bag to see what was happening and there was Debbie! She had found a good hiding place too! "Hey!", Debbie said, "What was wrong with you, anyway?"

Why did you have to go to the hospital?" (What do you think she told Debbie?)

One morning about three weeks later, Susan came running down the stairs screaming, "Mommy! Mommy! Come quick! My hair is falling out!".....(...I don't know what to write here at all. What do you think happened next? What did mother do? What did Susan do? Why did the hair fall out?)

About a year later, Susan was feeling much better. Her hair had grown back, and this time it was curly! She wasn't tired or sick anymore. The doctor at the clinic said that the medicines were doing a good job of killing the bad germs in Susan's body. She was very glad to hear that, because she had noticed that some of the other children at the clinic were very sick and they were taking the same medicines as Susan. A few earlier, one of the children got so sick that he died. It was very sad for Susan. Sometimes she wondered if she would die too.....(This is a hard part, what should I put about Susan dying? Do you think Susan would have talked to her mother or father about it? What would they have said?)

Having (the child's illness) was not always bad, though. One time Susan and her whole family got to go to Disney World for a vacation.....(This is a fun part...Did you ever get to go there? Well, then tell me what to write in this part.)

Another time Susan got to go to Camp Fantastic. It was so much fun she did not want to come home....(What do kids do at Camp Fantastic?)

(I don't have anymore...what else should I write? What happened to Susan after this part? How should the story end?)

(You have been a great helper. I could never have finished my book without you! Are you tired?...or can you draw a picture for the book? I will really put your picture in the book. What part do you want to draw? You can draw two if you want.....Tell me about this picture...where does it go in the book? Ok..one last thing. I want you to write your first name on this page, just the way you want it to be in the book, because when I publish my book, your name will be there too..as my helper, OK? Thank you for your help...you did great!!!)

Interview Guide : Parent's Interview

The following guide was used for the parent interviews with appropriate changes to suit the gender of the parent being interviewed, the gender of the child with cancer, and the marital situation.

Tell me about your family (number of children, ages, father's and mother's occupations, etc).

What type of cancer does (child's name) have? How long has (he/she) been in treatment?

Could you tell me about the events that led up to (child's name) diagnosis of cancer?

When you were told that (he/she) had cancer, what were your thoughts? How did you feel?
What did you do?

What about your husband? How did he think? Feel? Act?

Did (child's name) know what was happening? How did he react? Did (he/she) give any indications as to what (he/she) was thinking or feeling?

Did (he/she) say anything that gave you insight into how (he/she) understood what was happening to (him/her)?

Tell me about (his/her) first hospitalization. How did (he/she) react?

How did (he/she) handle the painful treatments? the nausea?

How were you and your husband coping during this time? What did you think? How did you feel? What did you do?

What actions did you take to assist (child's name) in coping?

What happened to the family after (child's name) came home from the hospital that first time?
Thoughts? Feelings? Actions?

How did (child's name) feel about going to the clinic the first time after discharge from the hospital? How did (he/she) act?

Were there any family members, neighbors, church groups etc that helped the family during the time immediately after diagnosis? Community agencies? How did they help?

Did (child's name) lose (his/her) hair as a result of the chemotherapy? What did you and your husband think? feel? do?

How did (child's name) react to being bald? Other children in the family? neighborhood?

What did you do to help (child's name) cope with the loss of (his/her) hair?

Did (child's name) ever say anything that gave you some insight as to why (he/she) believed (he/she) had lost his hair?

Have (child's name) changed the way (he/she) reacts to painful procedures, etc since (he/she) was first diagnosed? In what way?

Has (child's name) ever said anything that indicated that (he/she) may be worried about dying? What?

Have you ever talked to (child's name) about the possibility of death? What happened?

What support have you gotten from family, friends, neighbors, community agencies since the time (child's name) was first diagnosed?

How many times has (child's name) been hospitalized? Have you seen any changes in the way (he/she) reacts to the stress of hospitalization over time? What changes?

At this point in (child's name) treatment, how are you thinking? Feeling? Acting? What about your husband?

How is (child's name) adjusting to his illness? What does he think? How does he feel? How does he act?

Does (he/she) ever talk about (his/her) future? What does he say?

Is there anything else you can tell me that will help me understand how (child's name) and the rest of the family are coping with this battle with cancer?

Interview Guide: Institution Representatives

Tell me about your job responsibilities as they relate to children with cancer.

How long have you been working in this capacity?

What made you desire to work with pediatric cancer patients?

How do parents react when they are told that their child has cancer? What are their initial concerns?

At what point are the children told that they have cancer? How are they told? Who tells them?

How do children react when they are told about their diagnosis?

What comments have children made that gave you insight into how they perceive the origin and treatment of their cancer?

How do children react to their first experiences with painful treatments such as bone marrow aspirations? lumbar punctures?

What do you do to help them cope?

How do the children tend to react to the nausea and malaise they experience after chemotherapy?

What do you do to help them cope?

How do the children react to the loss of their hair as a result of chemotherapy?

What do you do to help them cope?

Have any of the children ever made comments to you about the possibility of their death? What have they said?

How do you talk to them about death? How do you help them cope?

Have you noticed if children's coping behaviors change over the course of treatment? In what way?

How about parents coping behaviors? Do they also change? In what way?

How do children react as they are approaching death?

How do you help them cope?

What impact do you see yourself as having on the entire family of the child with cancer?

Are there any community agencies that you recommend for helping the children and their families cope? Could you tell me about them?

What kind of a relationship do you observe between the children and their mothers? fathers? siblings?

How does the presence of cancer within the family place strain on the relationship between the mother and the father?

How do you help them cope?

What seems to be the most stressful part of treatment for the children? the parents?

Is there anything else you can tell me that will help me understand what child and the family think? Feel? Act?

Interview Guide: Community Agency Representatives

Tell me about your job responsibilities as they relate to children with cancer.

How long have you been working in this capacity?

What made you desire to work with pediatric cancer patients?

What services does your agency offer to children with cancer and their families?

Have children ever made comments to you that gave you insight into how they perceive the origin and treatment of their cancer? What?

In your experience, how do children react to the loss of their hair as a result of chemotherapy?

Does your agency offer any assistance for helping them cope?

Have any of the children ever made comments to you about the possibility of their death?
What have they said?

Do you ever talk to them about death? How do you help them cope?

Have you noticed if children's coping behaviors change over the course of treatment? In what way?

How about parents coping behaviors? Do they also change? In what way?

How do children react as they are approaching death?

How do you help them cope?

What impact do you see yourself as having on the entire family of the child with cancer?

What kind of a relationship do you observe between the children and their mothers? fathers? siblings?

How does the presence of cancer within the family place strain on the relationship between the mother and the father?

Is there anything else you can tell me that will help me understand what child and the family think? Feel? Act?

Or how you help them to cope?

APPENDIX B

CONSENT TO PARTICIPATE IN RESEARCH

Purpose of Research:

The purpose of this research is to discover the experiences of families who have a child who is being treated for cancer. The research will focus on the child, but will involve the child, parents, institution, and community. Children and their parents who agree to participate will be interviewed in their homes. The personal interview will take approximately 2 hours. The child will be asked to assist me in writing a book about a child who is sick. Some parts of the book are written, but the child will be asked to help fill in the empty parts. Both the interviews with the parents and the children will be tape recorded for later transcription.

Representatives of the institution and community agencies will be interviewed in their homes or offices, as they prefer. These interviews will take one or two hours and will be tape recorded for later transcription.

Confidentiality:

Names of participants and all identifying information will be excluded from the research report. Participants will be referred to by other names. Even the name of the hospital will be changed to protect the identity of the participants. The children will be given the opportunity to write their first names on the title page of the book, if they wish, so that they can be listed as part authors when the book is published. If the parents prefer that the child's name not be listed, this can be easily accommodated.

Consent:

Adults are asked to sign below if they agree to participate in this research project. Your consent is greatly appreciated. Parents are asked to give permission for both their own interviews and the interviews of the children. The child's verbal consent will be tape recorded if they agree to participate in writing the book.

Please check all that apply:

____ I consent to participate in this research project.

____ I give permission for my child to be interviewed.

Signature_____

Address_____

Phone number_____ Date_____

APPENDIX C

Coding Scheme

Reactions and Interactions:

RDK -Reactions/Diagnosis/Children

Comments by the children or about the children that showed how they reacted to diagnosis

RDF -Reactions/Diagnosis/Family

Comments by the parents that illustrated how they and other family members reacted and interacted during the diagnosis phase

RDI -Reactions/Diagnosis/Institution

Comments by institutional representative that reflected how the family reacted and interacted during the diagnosis phase and comments by anyone about how the institution staff assisted the family during that time

RDC -Reactions/Diagnosis/Community

Comments by community agency representatives that reflected how the family reacted and interacted during the diagnosis phase and comments by anyone about how the agencies assisted the family during that time

RTK -Reactions/Treatment/Children

Comments made by the children or about the children that showed how they reacted to the treatment phase

RTF -Reactions/Treatment/Family

Comments by parents that illustrated how they and other family members reacted and interacted during the treatment phase

RTI -Reactions/Treatment/Institution

Comments made by institutional representatives that reflected how the family reacted or interacted to the treatment phase and comments by anyone about how the institution staff assisted the family during that time

RTC -Reactions/Treatment/Community

Comments made by community representatives that reflected how the family reacted

and interacted during the treatment phase and comments by anyone about how community agencies assisted the family during that time

RCK -Reactions/Completion/Children

Comments by the children or about the children that illustrated how the children reacted to completion

RCF -Reactions/Completion/Family

Comments made by the parents that illustrated how they and other family members reacted and interacted during the completion phase

RCI -Reactions/Completion/Institution

Comments made by institutional representatives that reflected how the family reacted or interacted during the completion phase and comments by anyone about how the institutional staff assisted the family during that time

RCC -Reactions/Completion/Community

Comments made by community representatives that reflected how families reacted and interacted during the completion phase and comments by anyone about how community agencies assisted the family during that time

Pain and Sickness:

PDK -Pain/Diagnosis/Children

Comments by or about the children that reflected how they coped with pain and sickness during the diagnosis phase

PDF -Pain/Diagnosis/Family

Comments by the parents that reflected how they coped with the child's pain and sickness during the diagnosis phase and descriptions of how they assisted the children in coping during that time

PTK -Pain/Treatment/Children

Comments by or about the children that reflected how they coped with pain and sickness during the treatment phase

PTF -Pain/Treatment/Family

Comments by the parents that reflected how they coped with the child's pain and

sickness during the treatment phase and descriptions of how they assisted the children in coping during that time

PPI -Pain/Process/Institution

Comments made by anyone that reflected how the institutional staff assisted the parents and children as they coped with pain and sickness throughout the illness process

Hospitalization:

HDK -Hospital/Diagnosis/Children

Comments made by or about the children that illustrated how they coped with hospitalization during the diagnosis phase

HDF -Hospital/Diagnosis/Family

Comments by parents that reflected how they and other family members coped with the child's hospitalization during the diagnosis phase and what they did to assist the child in coping

HTK -Hospital/Treatment/Children

Comments made by or about the children that illustrated how they coped with hospitalization during the treatment phase

HTF -Hospital/Treatment/Family

Comments by the parents that reflected how they and other members of the family coped with the child's hospitalization during the treatment phase and what they did to assist the child in coping

HPI -Hospital/Process/Institution

Comments made by anyone that reflected how the institutional staff assisted the child and the family during hospitalization

HPC -Hospital/Process/Community

Comments made by anyone that reflected how the community agencies assisted the child and the family during hospitalization

Baldness:

BDK -Baldness/Diagnosis/Children

Comments by or about the children that illustrated how they coped with baldness during the diagnosis phase

BDF -Baldness/Diagnosis/Family

Comment by the parents that reflected how they and other family members coped with the child's baldness during the diagnosis phase and what they did to assist the child in coping

BTK -Baldness/Treatment/Children

Comments by or about the children that illustrated how they coped with baldness during the treatment phase

BTF -Baldness/Treatment/Family

Comments by the parents about how they and other family members coped with the child's baldness during the treatment phase and what they did to assist the child in coping

BPI -Baldness/Process/Institution

Comments by anyone that reflected how the institutional staff assisted the children and their families cope with baldness during the illness process

BPC -Baldness/Process/Community

Comments made by anyone that reflected how the community agencies assisted the children and their families cope with baldness during the illness process

Fear of Death:

FDC -Fear/Diagnosis/Children

Comments made by or about the children that reflected their fear of death during the diagnosis phase

FDF -Fear/Diagnosis/Family

Comments by parents that illustrated how they and other family members coped with fear for the child's death during the diagnosis phase and what they did to assist the child in dealing with fears of death during that time

FTC -Fear/Treatment/Children

Comments made by or about the children that reflected their fear of death during the treatment phase

FTF -Fear/Treatment/Family

Comments made by the parents that illustrated how they and other family members coped with fear for the child's death during the treatment phase and what they did to assist the child in coping with fears of death during that time

FCC -Fear/Completion/Children

Comments made by or about children that reflected their fear of death during the completion phase

FCF -Fear/Completion/Family

Comments made by parents that illustrated how they and other family members coped with fear for the child's death during the completion phase and what they did to assist the child in coping with fears of death during that time

FPI -Fear/Process/Institution

Comments made by anyone that reflected what the institutional staff did to assist children and their families in coping with their fears of death during the illness process

FPC -Fear/Process/Community

Comments made by anyone that reflected what the community agencies did to assist children and their families in coping with their fears of death during the illness process

Actual Death:

APC -Actual Death/Process/Children

Comments made by or about dying children that illustrated how they coped with dying

APF -Actual Death/Process/Family

Comments made by parents that reflected how they and other family members coped with the death of the child and how they attempted to recover and keep the child's memory alive after the death

APPENDIX D

VITA

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EDUCATION

Doctor of Philosophy, 1992

College of Human Resources, Department of Family and Child Development
Virginia Polytechnic Institute and State University, Blacksburg, Virginia

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Dissertation: Thoughts, Feelings, and Actions: A Retrospective Study of the Coping
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Masters of Nursing Science, 1987

University of Virginia, School of Nursing
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Liberty University, Department of Nursing
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PROFESSIONAL EXPERIENCE

1987 - 1992 Assistant Professor of Nursing
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Teaching Areas: Pediatrics, Pharmacology,
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1985 - 1986 Instructor of Nursing
 Lynchburg General School of Nursing
 Teaching Areas: Pediatrics and Community
 Health

1974 - 1985 Staff nurse with Centra Health
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 Work Areas: Obstetrics, Recovery Room,
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CURRENT PROFESSIONAL RESPONSIBILITIES

Coordinator for Junior Level Coursework, Department of Nursing

Co-Chair of the Curriculum Committee, Department of Nursing

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INVITED PRESENTATIONS

Family Planning Methods. Presented to Human Ecology Majors, Liberty University.

Nursing Care of Children with Nephrosis. Presented to the Pediatric Nursing Staff, Virginia Baptist Hospital.

Nursing Opportunities in the 90's. Presented to senior nursing students at a monthly meeting of the Liberty Nursing Student Association.

Safety Considerations When Caring for Infants and Toddlers. Presented to nursery workers, Thomas Road Baptist Church.