

Abstract

MARASCA, ERIN KATHLEEN. Long-term Effects of Pediatric Cancer on Siblings: A Qualitative Analysis. (Under the direction of Ann C. Schulte, Ph.D.)

Eleven siblings of pediatric cancer patients between the ages of 15 and 18 and their parents participated in a qualitative study of siblings' long-term adjustment to pediatric cancer. The qualitative design included two methods of data collection from the same informant (i.e., individual interviews and group interview with siblings), and two different informants (i.e., siblings and parents). Siblings and their parents were interviewed separately about (a) how illness-related information was communicated at the time of diagnosis, (b) initial concerns and coping strategies at the time of diagnosis, (c) changes occurring in the family during the initial phases of treatment, (d) other changes that occurred in the siblings' lives during this time, (e) the siblings' current functioning, and (f) areas for intervention and general thoughts regarding the cancer experience as a whole. Greater confidence was placed in findings that were reported by the majority of participants and across data collection methods. In terms of long-term adjustment, content analysis of sibling and parent interviews revealed ongoing fears about the sibling treated for cancer (i.e., relapse, ability to function independently), a continued sense of responsibility for the treated sibling, and residual feelings of guilt relating to their behavior during the patient's treatment, as well as the desire to pursue their own goals. Parents appeared to be largely unaware of the siblings' affect during treatment and currently. Intervention strategies considered helpful by the siblings included an increase in the amount of illness-related information given to them during treatment, as well as more support services, either through individual counseling or support groups.

Long-term Effects of Pediatric Cancer on Siblings:

A Qualitative Analysis

by

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A dissertation submitted to the Graduate Faculty of
North Carolina State University
in partial fulfillment of the
requirements for the Degree of
Doctor of Philosophy

PSYCHOLOGY

Raleigh

2003

APPROVED BY:

Chair of Advisory Committee

Dedication

This dissertation is lovingly dedicated to my parents, Alfred and Andrea Marasca, who never failed to provide the encouragement necessary to achieve my goals. Their dedication, patience, and endless support helped to make this project possible.

Personal Biography

Erin Marasca was born and raised in Los Angeles, California. She received her Bachelor of Arts degree in Psychology from the University of Southern California, her Master of Arts degree in School Psychology from California State University, Northridge, and her Doctor of Philosophy degree in Psychology from North Carolina State University. During her years at NCSU, Erin completed additional coursework and supplementary training in pediatric psychology at the University of North Carolina, Chapel Hill and Duke University. She completed an APA accredited predoctoral internship in pediatric psychology at Columbus Children's Hospital in Columbus, Ohio. Erin is currently a postdoctoral fellow at Nemours Children's Clinic in Jacksonville, Florida working primarily with pediatric oncology patients and their families. Areas of interest and specialty include facilitating adaptive coping and adjustment to chronic medical conditions, evaluating neurocognitive late effects of cancer treatment, and promoting pediatric palliative care.

Acknowledgements

I would like to gratefully acknowledge all of the people who assisted with this project and supported me throughout my graduate training. First, special thanks to my dissertation advisor, Dr. Ann Schulte, who provided helpful suggestions and invaluable guidance. Thank you for all the timely revisions, especially long-distance, as well as all the much needed confidence builders. I am also grateful to Dr. Marge Terhaar-Yonkers for stepping in as a committee member, and teaching me to appreciate the bittersweet nature of qualitative analysis. Also, to committee members, Drs. Patricia Collins and Lynne Baker-Ward, thank you for your important contributions.

For their direct involvement in this project, I would like to sincerely thank the participants in this study (i.e., the eleven “siblings”) for opening their hearts, and allowing readers to catch a glimpse of what it is like to live with a sibling with cancer. You are all truly courageous and special young adults.

My path to pursuing a career in pediatric psychology was not only encouraged and supported by my committee members, but was also shaped by educators and professionals in the community. I would like to thankfully acknowledge Drs. Stephen Hooper and Kenneth Whitt at UNC-Chapel Hill for providing specialized clinical training and supervision in working with medically challenged children and their families.

I continued to receive invaluable training in pediatric psychology during my internship at Columbus Children’s Hospital. I would like to thank my primary supervisor, Dr. Tammi Young-Saleme, for her professional guidance and ongoing opportunities to work with pediatric oncology patients. Thank you for modeling superior professionalism while never losing sight of true compassion. In addition, special thanks

to my other supervisors, Drs. Linscheid, Yeates, Colvin, Alioto, and Lemanek, for providing a multitude of excellent training opportunities, both in assessment instruments and therapeutic techniques.

My work at Nemours Children's Clinic in Jacksonville, Florida has afforded me exiting and challenging opportunities for growth. I would like to thank my primary supervisor, Dr. Lisa Schilling, for her excellent guidance and knowledge in working with pediatric oncology patients and their families. Thank you for your confidence in allowing me the independent experience, while always being available for supervision when needed. I would also like to thank my other supervisors and colleagues within the Divisions of Psychology/Psychiatry and Hematology/Oncology for their helpful suggestions, as well as providing such an enjoyable work environment.

The support of my family and friends has always been an important part of my educational success. As noted in the Dedication of this work, special thanks to my parents for their ongoing encouragement. Also, to my many friends, thank you for always believing in me and my ability to reach my goals. I would like to personally acknowledge Alan, Kim, Bonnie, Lynn, Greg, Peter, and Chuck for your enduring patience, as well as tolerating all the 'difficult' times.

Lastly, and perhaps most importantly, I want to acknowledge all the patients who have touched my life and continue to make my work so rewarding and memorable. First, to the ones who have fought and beaten cancer, or who are struggling with this disease on a daily basis, Kelley, Jeramy, Eva, Stephanie, and Taylor, I will forever admire your strength and determination to survive. You are an inspiration to everyone you meet. And...to the ones who fought diligently, but unfortunately passed on, Nick, Bobby,

Sarah, Brandy, and Kristin, your memories will be cherished forever. You are all angels who have moved onward. Thank you for sharing your lives with me and showing me the strength of a child's spirit.

This research was supported, in part, by a grant provided by the Cancer Education Project at University of North Carolina, Chapel Hill.

Table of Contents

List of Tables	x
List of Figures	xi
CHAPTER I: Introduction	1
CHAPTER II: Review of the Literature	6
Survival Rates in Pediatric Cancer	6
Cancer and Family Functioning	9
• General Effects.....	9
• Family as a System	12
• A Model of Family Functioning and Child Development	14
– Patterson’s Model.....	14
– Developmental Considerations.....	19
– Parenting Practices	22
– Contextual Variables	29
Adjustment Difficulties in Siblings of Pediatric Cancer Patients.....	33
• Overview.....	33
• Methodological Issues	36
– Short vs. Long-term.....	36
– Quantitative vs. Qualitative.....	37
– Parental vs. Self-Report.....	38
– Wide vs. Narrow Age Range.....	42
– Surviving vs. Deceased Sibling.....	42
• Behavioral and Emotional Outcomes for Siblings.....	44
– Findings from Chronic Illness Literature	44
– Findings from Cancer Literature	47
• Social Adjustment	60
• Academic Adjustment.....	63
• Positive Outcomes	65
• Coping with Demands Associated with Pediatric Cancer	67
Summary and Conclusions	68
Utilizing and Evaluating a Qualitative Research Design.....	71
• Introduction to Qualitative Methods.....	71
• Evaluating Qualitative Designs.....	74

CHAPTER III: Statement of the Problem and Research Questions	78
CHAPTER IV: Method.....	84
Participants	84
Instruments	87
• Time-Line Exercise.....	87
• Individual Interview Protocol	89
• Group Interview Protocol	93
• Parent Interview Protocol	95
Procedure	97
• Setting	97
• Recruitment.....	98
• Consent	100
• Time Line/Individual Interviews	100
• Group Interview	101
– Preliminary Analysis	101
– Interview.....	102
• Parent Interviews	102
CHAPTER V: Results.....	103
Description of Data Analysis Strategy.....	103
Results.....	105
• Research Question One.....	105
• Research Question Two	111
• Research Question Three	114
• Research Question Four	125
• Research Question Five	133
• Research Question Six	141
Additional Results.....	144
CHAPTER VI: Discussion	146
• Research Questions.....	146
• General Discussion	157
– Limitations.....	160
– Future Directions and Practical Implications	161
– Implications for School Psychologists	163
• Conclusion	165

References.....	167
Appendices.....	187
• Appendix A: Time-Line Exercise.....	188
• Appendix B: Individual Interview Protocol	191
• Appendix C: Group Interview Protocol	193
• Appendix D: Parent Interview Protocol	195
• Appendix E: Introductory Letter	197
• Appendix F: Consent to Participate in Research Study	198
• Appendix G: Background Questionnaire.....	200
• Appendix H: Project Evaluation.....	201

List of Tables

Table 1	Common Sites and Survival Rates of Childhood Cancer	7
Table 2	Demographic Characteristics of Participants.....	85
Table 3	Diagnosis and Treatment of the Participants' Siblings.....	86
Table 4	Instruments Used in Investigation and Links to Research Questions.....	88
Table 5	Percentages of Responses to Details of Information Provided At Time of Diagnosis.....	106
Table 6	Percentages of Responses to Most Significant Concerns at Time of Diagnosis.....	112
Table 7	Percentages of Sibling, Group, and Parents Who Endorsed Salient Changes of Cancer Experience	115
Table 8	Percentages of Responses to Sibling's Current Concerns and Overall Functioning	124
Table 9	Percentages of Siblings and Parents Who Endorsed Previous and Current Coping Strategies and Helpful Interventions.....	134
Table 10	Percentages of Siblings and Parents Who Endorsed Positive Changes Due to Cancer Experience.....	142

List of Figures

Figure 1 Patterson's Model of Antisocial Behavior Adapted to Sibling
Adjustment to Pediatric Cancer 17

CHAPTER I: INTRODUCTION

Background and Rationale

Advances in the treatment for cancer have significantly altered the prognosis for pediatric cancer patients over the last 30 years. Pediatric cancer has changed from an acute and inevitably fatal disease to one that is likely to be survived. New treatment protocols, which include combinations of chemotherapy, radiation, and sometimes surgery, are responsible for this improvement in prognosis. However, these treatment protocols are intense, long, and often result in uncomfortable or painful side effects (Carpenter & Levant, 1994).

Children with cancer now face months or years of treatment with still uncertain outcomes. These treatments are costly, disruptive to family routines, and require the family to adjust to a child who is chronically ill and has increased medical and emotional needs. Treatment may require separation of family members if treatment is not provided locally, drops in family income when one parent takes a leave from a job to care for the sick child, and increased involvement of extended family members in household routines.

A number of researchers have examined the impact of pediatric cancer and other chronic illnesses on children's development (Cadman, Boyle, Szatmari, & Offord, 1987; Fletcher & Copeland, 1988; Gortmaker, Walker, Weitzman, & Sobol, 1990; Greenberg, Kazak, & Meadows, 1989; Koocher & O'Malley, 1981; Madan-Swain & Brown, 1991; Mulhern, Carpentieri, Shema, Stone, & Faircloth, 1993; Ochs et al., 1991; Peckham, Meadows, Bartel, & Marrero, 1989; Pless, 1984; Sanger, Copeland, & Davidson, 1991). The cancer experience has the potential to affect cognitive, social, and affective development through a number of pathways. These effects may be direct, as in the case of

lasting central nervous system impairment as a result of chemotherapy, or indirect, as in the case of lowered achievement as a result of frequent school absences.

But pediatric cancer's potential effects are not limited only to the patient (Koocher & O'Malley, 1981). The sibling of a child with cancer also faces a changed context for his or her development. The illness may elicit feelings of rejection, isolation, depression, and anxiety in the sibling. His or her sense of control over the environment may be diminished, either by the illness itself, or by parents' lack of responsiveness as they attend to the needs of the sick child, as well as to their own grief and anxiety. Parental monitoring, school attendance, and extracurricular activities may all be disrupted. The diagnosis of cancer is certainly a time of emotional distress and upheaval for the family, but only just the beginning of a long-term process of family reorganization and adjustment (Brett & Davies, 1988; Koocher & O'Malley, 1981).

A number of studies have documented short-term adjustment difficulties in siblings of pediatric cancer patients. Using a variety of instruments, informants, and designs, decrements in siblings' functioning in the affective, behavioral, academic, and social domains have been found during treatment for childhood cancer (Bendor, 1990; Dolgin et al., 1997; Iles, 1979; Koch, 1985; Koch-Hattem, 1986; Kramer, 1984; Sahler & Carpenter, 1987; Sahler & Carpenter, 1988; Schuler, Bakos, & Zsambor, 1985; Walker, 1988).

A much smaller number of studies have examined siblings' long-term adjustment (i.e., three or more years after initial diagnosis). Despite the fact that treatment has ended and family routines no longer need to accommodate a sick child, it seems reasonable to suspect that there may be lasting effects for the sibling. Although individual experiences

may vary, as a group siblings have faced loss, uncertainty, significant family stress, home and school disruption, diminished parental responsiveness, and increased demands for independence. Some researchers have even suggested that siblings of long-term survivors may be at a higher risk for psychosocial problems than the patients themselves, given that parents' and professionals' attention is focused on the more salient needs of the cancer patient over the course of the illness (Cairns, Clark, Smith, & Lansky, 1979; Gogan, Koocher, Foster, & O'Malley, 1977; Spinetta, 1981).

Studies of both the short-term and long-term sibling effects have followed two major methodological paradigms: quantitative and qualitative. Quantitative studies have typically examined siblings' adjustment using rating scales designed to assess child psychopathology. Although such instruments are useful for examining whether childhood cancer increases the prevalence of specific disorders in siblings, they may miss milder adjustment difficulties. Rating scales that are focused on childhood disorders may also miss changes that are not necessarily pathological, but simply different. For example, childhood cancer may make a sibling more likely to attend college close to home in order to remain in contact with the cancer survivor. This subtle effect may be missed in studies which only examined child psychopathology.

Qualitative designs have the potential to detect effects of cancer on sibling adjustment that might be missed with quantitative designs. A number of qualitative studies of sibling adjustment have been conducted. These studies have largely consisted of open-ended interviews or surveys. However, the majority of the studies have assessed siblings shortly after diagnosis or during the initial phases of treatment. There is little information available about the long-term effects of childhood cancer on siblings, or on

what aspects of cancer siblings view as most salient years after diagnosis and treatment. The lack of studies employing a qualitative approach to assess long-term sibling adjustment is unfortunate because many aspects of qualitative methodology are ideally suited to understand the long-term impact of cancer on siblings. Long-term effects of cancer on siblings are likely to be more subtle than short-term effects, and more variable. The richer descriptions yielded by allowing respondents to speak for themselves in qualitative designs, and the emphasis on deriving themes from the data are useful tools for early inquiries into domains where our understanding is limited.

The purpose of the present study was to examine siblings' perceptions of the cancer experience and their adjustment years after diagnosis and treatment. A qualitative design was employed and included two methods of data collection from the same informant (i.e., individual interviews and focus group with siblings), as well as two different informants (i.e., siblings and parents). Constant comparison and triangulation were used to derive common themes that arose for siblings concerning (a) their current adjustment; (b) salient aspects of the earlier cancer experience; and (c) past and present coping strategies. Findings from the study will contribute to the overall understanding of the cancer experience as seen through the eyes of siblings. A better understanding of the long-term adjustment and views of siblings of cancer survivors may be helpful in the design of support services for siblings who are just being introduced to the experience of cancer, particularly in assuring interventions anticipate both short-term and long-term issues to be faced by the child.

In the next chapter, research literature relevant to siblings short- and long-term adjustment to cancer will be presented. The review begins with a brief description of

cancer, treatment protocols, and the types of demands a cancer diagnosis places on the family during treatment.

Following this description, a general systems model of family functioning and its role in child adjustment is presented, drawing from Patterson's theory (Patterson, Reid, & Dishion, 1992) of family and parenting variables associated with the development of antisocial behavior. This model is then used as a framework for discussing how cancer treatment and its impact on family functioning might affect siblings' development and adjustment.

Studies of sibling adjustment are then reviewed, beginning with general chronic illness studies and then followed by findings from the cancer literature. The literature review concludes with a brief introduction to qualitative research.

CHAPTER II: REVIEW OF THE LITERATURE

Survival Rates in Pediatric Cancer

It is estimated that 8,200 children are diagnosed with cancer each year in the United States (Gold, 1999). The most common sites of malignancy found in children (see Table 1) include the blood (e.g., Acute Lymphoblastic Leukemia), the brain (e.g., Medulloblastoma), the lymph nodes (e.g., Hodgkin's/Non-Hodgkin's Lymphoma), the central nervous system (e.g., Neuroblastoma), the kidneys (e.g., Wilm's Tumor), and the bones (e.g., Osteosarcoma) (Gold, 1999).

There are three main treatment procedures used in the treatment of childhood cancer, chemotherapy, radiation, and surgery. Chemotherapy works by disrupting normal cell metabolism and preventing the proliferation of cancer cells, and is the primary treatment modality for leukemia. However, since leukemic cancer cells can gain access into the central nervous system, and chemotherapeutic agents generally cannot cross the "blood-brain barrier," the central nervous system thus becomes a "sanctuary" site for these cancer cells. In this case, radiation therapy can be utilized to gain access to the brain and sometimes the spinal cord (Powers, Vannatta, Noll, Cool, & Stehbens, 1995). Surgery is often the treatment of choice when the particular cancer is contained, which can result in the removal of an organ or a limb. These protocols may be used in combination, depending on the cancer's presentation, clinical manifestation, staging, and prognosis (Powers et al., 1995).

The majority of pediatric cancer patients (i.e., 94%) are treated at various cancer centers that are managed by one of two national collaborative groups (i.e., The Children's Cancer Study Group, The Pediatric Oncology Group) (Gold, 1999). These centers enroll

Table 1

Common Sites and Survival Rates of Childhood Cancer

Site/Type	Percentage of	Survival Rates	
	Childhood Cancers	1962	1998
Leukemia	30%		
Acute Lymphoblastic Leukemia		4%	73%
Brain Tumors	20%		
Medulloblastoma		10%	50%
Lymph Nodes	15%		
Hodgkin's Lymphoma		50%	90%
Non-Hodgkin's Lymphoma		7%	80%
CNS Tumors	8%		
Neuroblastoma		10%	56%
Kidney Tumor	6%		
Wilm's Tumor		50%	90%
Bone Tumor	5%		
Osteosarcoma		20%	70%
Ewing Sarcoma		5%	60%

children who are diagnosed with cancer to take part in clinical trials that are monitored by the National Cancer Institute. There are approximately 200 cancer centers across the United States, Canada, and Australia that administer medication trials to children with cancer. Currently, there are over 15,000 pediatric cancer patients who are being managed according to these research protocols. At each institution, each child is managed by a multidisciplinary team of physicians, scientists, and specialists (e.g., oncologists, radiologists, surgeons, pathologists, psychologists, etc.) who possess the skills necessary for an accurate diagnosis, effective treatment protocol, and aftercare plan. Since these trials have been found to be largely responsible for the dramatic improvements in the treatment of pediatric cancer (Bleyer, 1990), many families choose to participate in one of the clinical protocols, even if that means relocating to be near the treating facility.

Due to the large number of medication trials for pediatric cancer patients that have been running continuously over the past several years, new combinations of chemotherapy, radiation, and surgery have improved the chances for overall survival. Treatment issues now center around finding a balance between very aggressive treatment (which has lower relapse rates, but higher probability for second malignancies and long-term effects), and less aggressive treatment (which has decreased long-term effects, but potentially higher relapse rates) (Bleyer, 1990). Acute Lymphoblastic Leukemia, for example, can now be treated in more than 70% of cases, as compared to less than 5% in 1960. Similarly, brain tumors, which were treatable in only 10% of cases in 1960, are now responding to new combinations of chemotherapy, radiation, and surgery that have resulted in nearly half of the children achieving remission. Table 1 presents survival rates for the most common forms of childhood cancer (St. Jude's Research Hospital, 1998).

Currently, there are 180,000 childhood cancer survivors in the United States. By the year 2010, it has been estimated that one in every 250 young adults will be a survivor of pediatric cancer (Gold, 1999). Due to the increases in the survival rates of childhood cancer, families are now faced with new challenges. Instead of coping with the loss of a child, the family as a unit must learn how to cope with the many changes that result from cancer treatment, and learn how to adjust to new family patterns.

Cancer and Family Functioning

General Effects

The importance of the family in a child's development has been well recognized, especially for children facing significant stress such as living with a sibling who has an acute or chronic illness (Dolgin & Phipps, 1996). According to Sabbeth (1984), childhood illness affects a family across several dimensions including financial, logistical, social, and emotional/behavioral. When a child is diagnosed with an illness such as cancer, families may need to make decisions relating to the distribution of resources, both financial and emotional, which will have short and long-term consequences for all family members. For example, parents may decide to relocate in order to be closer to a particular treatment center or extended family members; one parent may decide to take a leave from their job to care for the ill child and transport him or her to clinic visits; leisure activities may have to be altered to accommodate the sick child's needs; and increased physical and emotional attention may be given to the sick child in the attempt to cope with the demands of the illness (Chesler & Barbarin, 1987; McKeever, 1983; Sabbeth, 1984).

Siblings are not immune to many of the family stressors that follow a diagnosis of pediatric cancer. They must learn how to cope with the consequences of the changes

resulting from the illness, such as adapting to increased physical and/or emotional distance from the primary caregiver, learning how to deal with heightened sibling rivalry resulting from increased attention to the sick child, and coping with emotions that typically are confusing, frightening, and frustrating (Chesler & Barbarin, 1987).

Decreased attention to siblings is not only observed in the homes of pediatric cancer patients. Much of the research focusing on psychosocial effects of pediatric cancer in siblings has mirrored this phenomenon. According to Chesler, Allswede, and Barbarin (1991), siblings have historically been used as control groups in studies centering on patients' needs, or in studies of family functioning where they are often mentioned only as a "family member." Not until recently have they been regarded as the primary focus of interest, as researchers began to discover that siblings may even have more adjustment difficulties than the patients themselves. To illustrate, Spinetta and Deasy-Spinetta (1981) conducted one of the first detailed, multi-faceted study of the effects of cancer on siblings. Results indicated that siblings were less well adjusted than the patients on a number of criterion measures including overall emotional adjustment, self-concept, and perceived parental distance. Similarly, Cairns et al. (1979) found that siblings displayed more distress than the patients in areas such as fear of expressing negative emotions, social isolation, and concern with school failure.

However, even with siblings receiving increased attention in studies of adjustment to pediatric cancer, the literature remains in an early, atheoretical phase. Most research studies have simply documented decrements in siblings' adjustment when a child undergoes cancer treatment without specifying the pathways or mechanisms that lead to these adjustment outcomes. There also have been few attempts to understand how a

range of factors, such as the sibling's age, the family context, the sibling's pre-cancer functioning, and the parents' coping strategies when facing cancer, interact to produce a range of outcomes for siblings.

Some researchers have included family factors in their analyses of sibling adjustment to the cancer experience (Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Dolgin et al., 1997; Haversman & Eiser, 1994; Horwitz & Kazak, 1990; Kramer, 1984; Koch, 1985), however, there have been no models or theories generated that use a family systems viewpoint (i.e., the effects of parenting and contextual variables) to understand siblings' adjustment when their brother or sister is diagnosed and treated for cancer. Given that no models exist in the pediatric cancer (or even chronic illness) literature that describe the interplay of child, family, and contextual variables and their impact on sibling adjustment, looking at general child development models that incorporate these variables seems a logical first step in moving this research area from atheoretical to more model-driven.

The review now turns to a discussion of families as systems, along with examples of researchers who have taken a family systems approach in evaluating individual child variables. The discussion will conclude with an examination of a model developed by Patterson and colleagues (1992) that focuses on the effects of contextual variables on individual child adjustment which are mediated by various parenting practices. The model was developed after extensive research with aggressive and antisocial children; however, its application and extension to siblings of pediatric cancer patients seems relevant given its focus on family disruption and its impact on child adjustment.

Family as a System

According to Hinde and Stevenson-Hinde (1988), when the family unit is challenged, family patterns change. An essential aspect in studying general family functioning, as well as family adjustment to a stressful event such as a life-threatening illness, is a viewpoint that acknowledges that change in one component of the family produces change in other elements of the family system. A general premise of the family system's viewpoint is that individuals in the system are interrelated and contribute to the organization of patterns and behaviors that characterize the family unit (Minuchin, 1988). According to Dolgin & Phipps (1995), instead of viewing the impact of childhood cancer on the family solely in a linear fashion, utilizing a more "systemic" approach, where the child and family are viewed as part of a larger network of extended family, work, and community resources, more accurately reflects reality.

When examining patterns of family relationships, researchers have historically focused on the mother-child subsystem due to the belief that this dyad was the most significant context for growth (Minuchin, 1988). Due to the increasing influence of using systems theory in studying family relationships, the focus of many studies has expanded to other subsystems in the family as well (e.g., father-child, sibling-child). However, what is still somewhat limited in the theoretical literature is the integration of family systems and developmental theories, as well as the effects the family as a system has on a child's (i.e., sibling's) individual development.

Several researchers have attempted to identify aspects of the individual's family and environment that contribute to their development. For example, Bronfenbrenner, in his "Ecological Developmental Theory," conceptualized individual development within

several layers of structures that are mutually influential in the developmental process (Bronfenbrenner, 1977). According to the theory, the “environment” in a child’s world is composed of structures that extend beyond the child’s immediate setting, and are regarded as having a powerful impact on the child’s individual development. The theory emphasizes that not only is the child influenced by settings he or she interacts with directly (i.e., microsystem), but is also influenced by settings connected to the family system that do not directly include him or her (i.e., exosystem), as well as society’s values, ideologies, laws, customs, and regulations that comprise the culture in which the individual child lives (i.e., macrosystem). In addition, individual development is facilitated by the reciprocal interconnections between and among all of the people, events, and settings in the child’s immediate environment (i.e., mesosystem). Therefore, significant events in the family (e.g., illness) can modify the existing relationships between the individual child (i.e., sibling) and his or her environment, which, in turn, produce new conditions that continue to affect the child’s development.

Other researchers have applied family environment and contextual factors to the examination of individual development in special populations. For example, Zeltzer, Bursch, and Walco (1997) investigated the assessment and psychobiological treatment of children who had chronic pain. These researchers identified crucial factors that contributed to the child’s pain perception. These factors included not only individual factors such as the child’s temperament, developmental level, and memory for previous painful experiences, but also involved family factors such as parental modeling and reinforcing.

Similarly, Patterson and his colleagues developed a contextual model for understanding how antisocial behavior in childhood is developed and maintained. Specifically, they examined how disruptions in key aspects of parenting lead to maladaptive and antisocial behavior in children and adolescents, and how these parenting strategies are affected by certain contextual factors (Patterson et al., 1992). Although Patterson's model focuses on the development of antisocial behavior, the model may also be applied more generally to examine other situations in which disrupted family functioning may have an impact on child development. Following is a description of Patterson's model, as well as a discussion of how the theory can be adapted to understand how pediatric cancer might affect the adjustment of siblings.

A Model of Family Functioning and Child Development

Patterson's model. Patterson and his colleagues' (1992) theory provides an empirical framework for understanding the development and maintenance of antisocial behavior in children and adolescents. The model provides an account of how the effect of various contextual factors on individual child development is largely mediated by certain parenting practices. Within the model, relationships between the contextual factors, parenting practices, and individual child development are bi-directional. Specifically, certain aspects of the child's environment can influence parenting skills and child adjustment, and changes in parenting practices or child development can alter some of the contextual variables. The parenting practices that play a central role in the model include (a) parental involvement (i.e., indirect measure of parental support where parents engage in activities with the child that are mutually enjoyable), (b) parental discipline (i.e., involving tracking behavior, ignoring trivial events, and using effective follow-through on

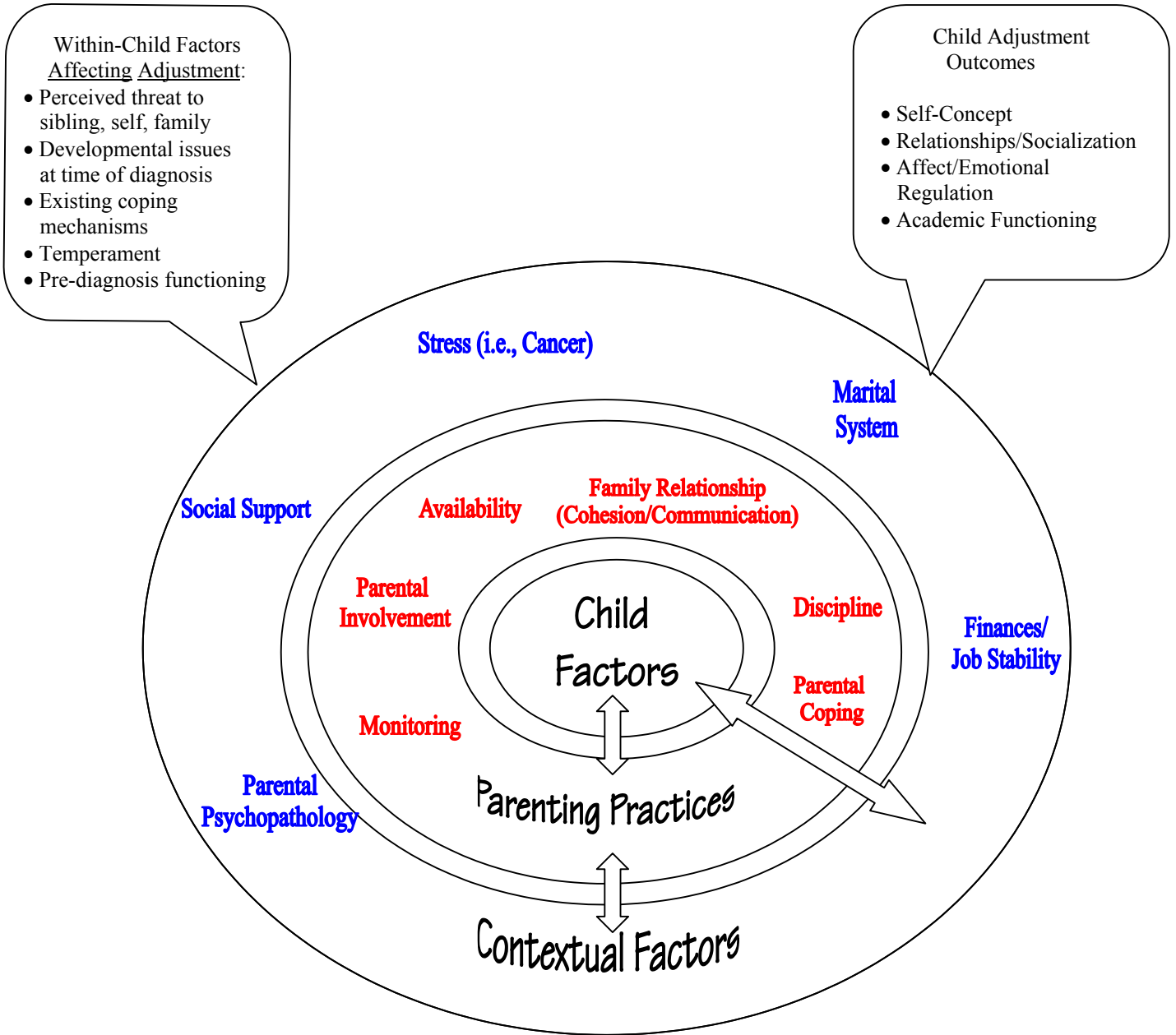
consequences), (c) positive reinforcement (i.e., tracking and reinforcing prosocial behaviors), (d) “dyadic” problem-solving (i.e., controlling negative affect while reaching compromises in solving daily conflicts), and (e) monitoring (i.e., knowing where child is, what activities they are engaged in, and with whom they spend their time). Contextual factors that are outlined in Patterson’s model include both “causal” (e.g., stress, transitions, and marital relationship), or “static” (e.g., family history, social disadvantage, and parental pathology) variables.

It is noted that the contextual components can be thought of as “risk” factors in relation to child adjustment, while effective parenting practices can be thought of as “protective” factors. Therefore, the impact of contextual stressors on individual child adjustment will depend on the use and consistency of parenting practices. However just as in Bronfenbrenner’s ecological theory, the interaction of the variables is likely to be very complex (Patterson et al., 1992). Understanding the contextual factors and the parenting practices that may influence child development can be a helpful way to conceptualize the effects of pediatric cancer on siblings.

Figure 1 illustrates how Patterson’s model can be adapted and extended to explain sibling adjustment to pediatric cancer. First, there are within-child factors that affect how a sibling will adjust to the cancer experience. These factors include (a) the sibling’s perceived threat of the illness on him or herself, the sick brother or sister, and the family, (b) the developmental stage of the sibling at the time of diagnosis (to be discussed later), (c) the sibling’s existing coping mechanisms, (d) the sibling’s temperament, and (e) the sibling’s pre-diagnosis functioning.

Figure Caption

Figure 1. Patterson's Model of Antisocial Behavior (Patterson, 1992) adapted to sibling adjustment to pediatric cancer



Second, there are “parenting practices” that can mediate the effect between contextual factors (e.g., cancer diagnosis) and sibling adjustment. These include (a) parental monitoring, involvement, and availability, (b) discipline practices of both the patient and healthy siblings, (c) the way parents cope with the illness and (d) levels of cohesion and communication that are characteristic of the family relationship. These parenting practices all have the potential to become disrupted when a child is diagnosed with cancer due to the reorganization of family patterns and routines in order to accommodate the sick child.

Lastly, along with the stress of the cancer diagnosis, there are other “contextual factors” that can influence parenting practices, which consequently, can also affect individual sibling adjustment. The contextual factors noted include (a) the strain on the parents’ marital relationship, (b) pre-existing or current parent psychopathology, (c) financial costs of the illness and the parents stability at work, and (d) parental social support.

All of these factors (i.e., within-child, parenting, and contextual) have the potential to affect individual sibling adjustment outcomes, which include how siblings view themselves, their future and their interpersonal relationships; their ability to be successful in school; and their capacity to regulate and manage their emotions. The next section will describe how siblings’ age is thought to affect their adjustment to pediatric cancer. The review will begin with a discussion of how pediatric cancer might affect infants and proceed through adolescence. Following this section will be a description of how parenting practices can be disrupted by contextual factors related to cancer and how the impact of this disruption can affect individual sibling adjustment.

Developmental considerations. The impact of pediatric cancer on a sibling can be expected to vary depending on age and developmental level. Differences in individual development will determine how a child views the illness (i.e., causality, prognosis), tolerates the loss of parental attention and availability, reacts to family separation, deals with changes in social activities and relationships, and copes with transitions in normal routines.

Infants are completely dependent on their primary caregiver to meet their physiological and emotional needs. When an illness such as cancer separates that primary caregiver from the infant, the infant's sense of trust, security, and attachment may be threatened. According to Lindsay and MacCarthy (1974), infant siblings of cancer patients were found to be at the highest risk for adjustment difficulties due to the mother's preoccupation with the sick child and inability to respond to the infant's cues. Similarly, Lansky, Stephenson, Weller, Cairns, and Cairns (1982) observed 65 infant siblings of pediatric cancer patients and found that a significant number of the infants displayed signs of failure to thrive. These researchers speculated that parental stress resulting from the illness contributed to the loss of physical and emotional attention.

Toddlers also have a difficult time understanding the parents' preoccupation with the sick sibling, and may interpret it as a rejection of themselves (Lindsay & MacCarthy, 1974). As toddlers tend to perceive the world as if they were in the center, and believe that everything that happens is either related to them or caused by them, they may have irrational views relating to the cause of the illness and their parents' reactions. Specifically, toddlers will either construct "magical links" in order to make sense of the illness, or believe that in some way they caused their sibling to get sick because they were

“mean” or did something wrong. The toddlers’ anxiety that often results from frequent separation of parents and inability to understand aspects of the illness, along with the perceived rejection, jealousy, and confusion resulting from decreased parental attention, could result in regressive behavior (e.g., bedwetting), temper tantrums, and/or appetite and sleep difficulties (Kramer, 1981).

Although the cognitive ability of school age children increases in complexity, leading to a better understanding of the causality of the illness, they still have a prominent need for factual information. According to Lindsay and MacCarthy (1974), school age siblings are generally very aware of the increased anxiety level in the family and may not only feel rejection, but also anger or resentment at what their sibling’s illness is doing to the family. Along with facing elevated anxiety in the family, school age siblings also have to deal with missing out on common childhood activities due to lack of parental attention and time, decreased financial resources, and increased responsibilities at home. Unfortunately, this anger and resentment for disrupting the family unit and restriction on vital activities may lead to feelings of self-doubt and inferiority, as well as to behavioral and emotional difficulties, poor school performance, and/or somatic symptoms (Johnson, 1997; Kramer, 1981)

The period of adolescence is a time typically spent securing independence, connecting more closely with peers, loosening ties with parents, developing a unique identity, and becoming increasingly self-sufficient (Kramer, 1981). However, for an adolescent whose sibling has been diagnosed with cancer, new demands at home typically cause the adolescent sibling to remain attached to the family and to the sick child’s needs. Parents may place additional restrictions and responsibilities on the adolescent sibling

which, consequently, affect the time spent establishing and maintaining peer bonds and engaging in extracurricular activities, as well as prolong dependence on parents. As noted with children in the younger age groups, adolescents may also react with anger and resentment to these changes, however, the adolescent sibling may act out even more so due to the perception that no one can possibly understand their situation. In addition, fearing to appear “different” than their peers, adolescent siblings may act embarrassed about the physical changes that occur in their sick brother or sister (e.g., hair loss, amputation), especially when they believe everyone around them notices these differences in the themselves and the sibling (i.e., imaginary audience). Due to advanced cognitive abilities, adolescent siblings are better able to comprehend aspects of the illness; however, they are also more aware of the potential complications of treatment, as well as their own vulnerability to illness, possibly leading to increased anxiety. Unfortunately, these feelings of anxiety, along with the resentment, jealousy, confusion, and anger that results from the demands of the illness, may go unrecognized as adolescents tend not to turn to parents as often for support. It is not uncommon for adolescent siblings of cancer patients to respond to these new demands and fears with antisocial behavior or rebelliousness (Johnson, 1997), or increased caretaking of the sick sibling as a form of defense (Lindsay & MacCarthy, 1974).

In sum, it is clear that the effects of cancer on siblings will depend greatly on the sibling’s age and developmental stage. Unfortunately, many studies assessing the effects of pediatric cancer on siblings use a wide age range in their analyses, but do not test the differences of effects on age (as described in a later section). When combining the significance of parental/familial factors described in the next section to the influence of

development on the sibling's adjustment to cancer, predicting adjustment outcomes becomes even more complex.

Parenting practices: Monitoring, involvement, and availability. As noted above, Patterson's model places great importance on parental monitoring and involvement in child adjustment. Although the mechanisms are quite different, cancer can also affect parental monitoring and availability. When a child is diagnosed with a life-threatening illness such as cancer, parental monitoring and involvement will most likely be disrupted due to the increased time and energy spent with the sick child. The illness may cause parents to be separated from the rest of the family due to hospital stays, which can result in less time allotted for healthy siblings. In addition, siblings typically are asked to take on additional responsibilities in the home to help with family functioning, as well to help with their brother or sister's treatment. Siblings, in turn, may respond to the decreased attention and involvement with feelings of jealousy, helplessness, shame, and/or guilt, which can lead to further emotional difficulties (Sourkes, 1980). To illustrate, Kramer (1984) interviewed 11 siblings of children with leukemia and found that two of the major themes generated by the siblings responses included difficulties with the separation of the family during treatment phases and the need to "emotionally realign" after diagnosis. Specifically, siblings reported decreased involvement with their parents and the sick child, and therefore, a lack of parental support. This author reported these siblings reacted to these stressors with increased anger and frustration, sibling rivalry, sadness, and guilt. Furthermore, this author stated that the siblings felt they should just tolerate their parents' preoccupation with the sick child and take on more responsibility, even if they did not agree.

Similarly, Sloper and While (1996) also found separation from parents and lack of attention as important risk factors for sibling adjustment. Specifically, these authors evaluated 99 siblings (ages 8-16) six months after the diagnosis of their brother or sister. Two of the most significant risk factors in child adjustment were (a) the number of nights the child was in the hospital (i.e., parental separation from siblings) and (b) the siblings' appraisal of the lack of time and attention their parents had for them.

Finally, Schuler et al., (1985) analyzed data from 75 families of pediatric cancer patients and found that healthy siblings were in the most "unfavorable" situation of all family members, in that the most significant factor was the dramatic reduction in communication and interaction with both their parents and their sick brother or sister.

Parenting practices: Differential treatment of sibling/inconsistent discipline.

According to Patterson's model, one of the parenting practices that can become disrupted due to the effects of various contextual variables is the consistency of discipline in the home. When parents are preoccupied with a stressor in their own lives, they have less energy, time, and sometimes patience to provide consistent levels of monitoring and discipline to the children. Although Patterson's model was developed considering the impact of contextual factors such as parent alcohol abuse or single parenting on discipline practices, providing discipline in a family with a child diagnosed with cancer can also become inconsistent. For example, parents may discontinue disciplining the sick child due to all the demands associated with enduring painful treatment. Healthy siblings, on the other hand, may receive more stringent discipline due to increased responsibilities at home, or decreased discipline due to less parental monitoring.

Differences in discipline practices between the ill and healthy child, along with increased attention, gifts, and privileges for the ill child has been found to elicit feelings of jealousy and resentment in siblings of pediatric cancer patients (Adams-Greenly, Shiminski-Maher, McGowan, & Meyers, 1987; Cunningham, Betsa, & Gross, 1981; Shepard & Mahon, 1996; Taylor, 1980). For example, Havermans and Eiser (1994) interviewed 21 healthy siblings of pediatric cancer patients and found that 12 out of 21 siblings reported differential treatment from their parents. Similarly, Chesler et al. (1991) interviewed 21 siblings (ages 10-21) and found that one of the major themes generated by the siblings' responses was differential treatment from parents. These siblings reported their parents being inconsistent with the discipline of the ill child. In addition, these authors stated that the siblings' perceptions of inequality of discipline often intensified emotional reactions such as anger and frustration.

Kramer (1981) indicated that siblings often resent the over-protectiveness and over-indulgence of the sick child by parents. Siblings were noted to complain to their parents that their brother or sister never receives discipline for misbehavior, and can often stay home from school when feeling ill, which are perceptions likely to be accurate. In addition, these complaints of favoritism become even more substantial for the sibling during periods of remission or when the illness is controlled due the fact that the child with cancer may look and feel well. The author noted that sibling rivalry, subsequent to these feelings of anger and jealousy, becomes intensified and may lead to hostility and exaggerated competitiveness. Unfortunately, these intense feelings of anger typically lead to feelings of guilt, resulting in the healthy sibling being ashamed over their feelings of anger or thinking bad thoughts regarding their brother or sister, or even about feeling

healthy themselves. This vicious cycle of anger and guilt, according to the author, may then provoke a variety of maladaptive behaviors in the healthy sibling.

Parenting practices: Coping. It has been suggested that the manner in which parents cope with stressors in their lives (e.g., illness and associated treatment) can have an impact on sibling and family adjustment. For example, Kaplan, Grobstein, and Smith (1976) evaluated coping strategies of 40 families of children diagnosed with leukemia, and how they were related to family problems. The authors labeled coping “adaptive” when the parents (a) comprehended the seriousness nature of the illness, (b) communicated the seriousness of the illness to the other children in the family, and (c) responded appropriately with feelings of grief and sadness without inhibiting emotional expression. After interviewing the parents of the children with cancer, the authors concluded that in the families who coped “adaptively,” only 1.5 family problems were reported. Conversely, in the families who had “maladaptive coping,” 8.3 family problems (including problems with siblings) were reported. Problems identified included marital, health, sibling’s behavior, and family relationships.

Parenting practices: Family relationship/cohesion. Several investigators have associated high family cohesion with less behavior problems reported in siblings of pediatric cancer patients. For example, Cohen et al. (1994) gave a number of standardized questionnaires to parents of 129 siblings of pediatric cancer patients to determine variables associated with good and poor adjustment. Results indicated that high levels of family cohesion (as measured by the FACES II) were significantly associated with less reported externalizing problems and higher social competency on the Child Behavior Checklist (i.e., CBCL). Similarly, high levels of family adaptation (as measured on the FACES II)

were significantly associated with less reported externalizing problems and higher social competency as measured by the CBCL.

Horwitz and Kazak (1990) also found that family cohesion was associated with fewer reported behavior problems in 25 preschool siblings of pediatric cancer patients. Specifically, high family cohesion was significantly related to fewer internalizing and externalizing behaviors as reported by parents.

Finally, Dolgin et al. (1993), in a cross-cultural investigation of Israeli and American siblings of pediatric cancer patients, examined the contribution of family relations and parental coping to sibling's emotional and behavioral adjustment. Results yielded significant correlations in both the Israeli and American samples between the family relations and coping variables and the sibling's CBCL scores, which indicated that greater family cohesion and internal support, increased emotional expressiveness, and lower family conflict were associated with less behavior problems in the siblings. Furthermore, one factor (i.e., support in the family) accounted for 54% of the variance in sibling problem behaviors.

Parenting practices: Family relationship/communication. Several investigators have reported the need for siblings to maintain communication with family members, to receive age appropriate disease-related information, and to be an active part of their brother or sister's treatment (Bendor, 1990; Brett & Davies, 1988; Iles, 1979; Martinson, Gilliss, Colaizzo, Freeman, & Bassert, 1990; Sahler & Carpenter, 1987; Walker, 1988). In a review of the literature on sibling adjustment to cancer, Carpenter and Levant (1994) found that some of the factors associated with poorer adjustment in siblings of pediatric cancer patients were insufficient or infrequent exchanges of information by their parents

about their sibling's illness, limited participation of healthy siblings in their brother or sister's treatment of cancer, feelings of physical and emotional isolation from their parents, and insufficient existing resources available to siblings to provide emotional, social, and peer support. Additionally, Kramer (1981) examined the impact of cancer in siblings of pediatric cancer patients and discovered three factors that siblings believed were crucial in facilitating adjustment. These factors included needing ongoing information about their sibling's illness and treatment, continuing to experience open and communication within the family, and desiring to be involved in their sibling's cancer experience.

Koch (1985) found that 14 out of 33 siblings interviewed reported difficulty in communicating with their parents and expressing emotion. They stated that they would rather not "bother" anyone with their emotions, and therefore, attempted to pretend they were not having the disturbing feelings.

Spinetta (1978) found that the level of sibling's feelings of anxiety and isolation was directly related to communication within the family. Specifically, in families where communication was more open and ongoing, siblings were reported to have higher self-esteem, less defensive attitudes, and increased closeness with family members. In addition, Havermans and Eiser (1994) found that the siblings in their study who reported high levels of communication in the families about the illness scored lower on a general impact scale, which indicated fewer behavior problems (significant at .05 level).

According to Gallo (1988) the reluctance of parents to discuss aspects of the child's illness and treatment with siblings may often reflect the lack of communication among family members in general. Featherstone (1980) postulated that parents may keep

disease-related information exchanged with healthy siblings to a minimum in order to decrease the likelihood that siblings will ask parents very difficult questions, which would threaten the parents own denial efforts. Therefore, avoidance may form an essential part of parental efforts to normalize their family situation with regard to the illness.

When disease-related information is not provided to healthy siblings by parents, and siblings are not given the external resources for information and support, siblings have been reported to rely on their own interpretations of their brother or sister's illness and prognosis. Unfortunately, siblings interpretations are usually based on parental reactions and overheard conversations, which may lead to a distorted picture of fear and anxiety about what will happen to the sick child and the family (Sourkes, 1980). According to Drotar & Crawford (1985), if siblings are not given opportunities for involvement and are misinformed, it is not uncommon for siblings to respond with isolation and feelings of anxiety and resentment.

In sum, several variables associated with parenting practices have been discussed and linked to individual child adjustment. Although Patterson and his colleagues developed their model to illustrate effects on antisocial children, many of the same variables can be applied to living with a child with cancer, in that much of parenting and what siblings know as "normal life" is disrupted when a child is diagnosed and endures months of painful treatment. It has been illustrated how disruptions in family monitoring, involvement, availability, coping, discipline, and interactions, brought on by the stress of cancer, can affect siblings own individual adjustment. What must also be considered are factors that can influence these parenting practices, and, subsequently, affect sibling adjustment to the cancer experience. As stated above, Patterson and his colleagues refer to

these contextual factors (e.g., marital relationship, parent psychopathology, job instability, financial status, outside social support, etc.) as “risk” factors that have the ability to affect sibling adjustment indirectly by disrupting parenting skills. Although many of the variables were not evaluated directly in the present study, understanding their impact on families when a child is diagnosed with cancer is important when considering sibling adjustment to the cancer experience. The variables will be discussed briefly.

Contextual variables: Marital relationship. When a child is diagnosed with cancer, many family components are taxed, including the relationship between the child’s parents. The marital relationship may be challenged by parents not spending as much time with their spouse, being preoccupied with the sick child’s needs when they are together, and possibly blaming each other or venting their anger on one another (Sabbeth, 1984). Sabbeth reviewed 34 research studies focusing on marital strain after the diagnosis of a pediatric acute illness and found that, although divorce was not more common among these families than controls, a higher level of marital stress was experienced. In addition, this author states that pediatric illness can have a negative impact on the marital system by increasing levels of stress in the family, which can escalate marital problems, which in turn, can affect the parent/child relationship.

Other researchers have noted an increase in marital problems after the diagnosis of childhood cancer. For example, Kaplan et al. (1976) evaluated 40 families of children with leukemia and found that 70% of the parents interviewed reported serious marital problems after the diagnosis of cancer. Similarly, Schuler et al. (1985) found that marital problems arose in one-half of the 81 families investigated. These authors stated that

although there tended to be some improvement in the marital relationship at the onset of remission, a complete return to “normal” life was rarely achieved.

Several researchers have found that the marital relationship is an important variable associated with individual child adjustment (Belsky, 1984; Caspi & Elder, 1988; Rutter, 1980). In a review of the literature on marital relationships and child adjustment, Emery (1982) found that marital conflict and general unhappiness were associated with behavior problems in children who had been referred to clinics for treatment. In addition, Brody, Stoneman, and Burke (1987) evaluated the effects of the marital relationship on child adjustment in 42 families. Results indicated that for younger children (i.e., 4.5-6.5 years of age), higher rates of prosocial behavior were most strongly associated with low levels of interparent conflict. For older children (i.e., 7-9 years of age), prosocial behavior was related to high marital quality. In addition, low marital quality was strongly related to acting out behavior in both the younger and older children.

In summary, although only reviewed briefly, it has been shown that problems in the marital relationship could affect many of the parenting skills described above (i.e., attention, availability, monitoring, consistent discipline, communication, etc.), especially when there is a child in the family diagnosed with cancer. When parents are concerned with the needs of the sick child, which could lead to marital strain, it is reasonable to assume that siblings will not have their needs completely met.

Contextual variables: Parental psychopathology. Research on the association between parent psychopathology and child adjustment has primarily focused on maternal depression and its influence on parenting skills. In general, researchers have found that mothers who are depressed are less involved with their children, experience difficulty in

managing their children's behavior, communicate less effectively with their children, and perceive their children as more poorly adjusted than non-depressed mothers (Brody & Forehand, 1986; Cohler et al., 1976; Griest, Wells, & Forehand, 1979; Radke-Yarrow et al., 1985; Weissman, Paykel, & Klerman, 1972). It is therefore reasonable to assume that parental depression, either preexisting or following the diagnosis of pediatric cancer, can challenge a parent's ability to cope with their own emotions, and consequently, can affect the parent's capability to allot time and energy for the sick child, let alone the healthy siblings (Kaplan et al., 1976).

Contextual variables: Finances/job stability. A chronic childhood illness, such as cancer can place very large financial demands on the family. In addition to the expenses incurred by the treatment of cancer, there are many expenses that are not covered by insurance companies, but are nonetheless essential to the well being of the child and family. Such expenses include food required by special diets, sitters for healthy siblings, transportation to clinic visits and hospital stays, cosmetics, wigs, structural changes to the home for easy accessibility, and counseling for family members. Parental job stability may be affected as well when a child is diagnosed with cancer. Parents may need to quit their job in order to care for the sick child, or move to a location closer to the treating facility.

Job-related problems in families of cancer patients have been noted in the literature. For example, Kaplan et al., (1976) evaluated 40 families of children with leukemia and found that 60% of the parents interviewed described serious problems at work. The family situation may become even more complicated when a parent is forced to stay at a job in order to maintain insurance benefits, even if it means a family separation (and consequently, decreased parental involvement, availability, and monitoring of

siblings), or increased irritability and stress on the part of the parent, which can also have an impact on the parent-child relation, and therefore, individual child adjustment.

Contextual variables: Parental social support. Although not investigated at great length in the literature, it has been noted that social support in the family is associated with individual sibling adjustment to pediatric cancer. For example, Sloper and While (1996) evaluated 99 siblings (ages 8-16 years) of pediatric cancer patients. After siblings and parents completed several standardized instruments assessing child adjustment and family relationships, the authors found that those siblings who were reported as having more behavior problems, were also the siblings with mothers who had significantly lower levels of outside social support. These authors stated that several of the mothers cited the importance of relying on friends and extended family to care for the siblings and help with the day-to-day maintenance of the home while the parents were with the ill child. Therefore, for those mothers who did not have this support available to them, siblings exhibited poorer adjustment. As in Patterson's model, parental support would be expected to have indirect effects on child adjustment because high support enables positive parenting practices while lack of support makes parental monitoring and involvement difficult, and may reduce the parents' ability to respond consistently and positively when they are available to the sibling.

In summary, when examining sibling adjustment to the experience of pediatric cancer, it appears best to use a systemic approach that incorporates reciprocal influences within the family unit (Dolgin & Phipps, 1996). Patterson's model is a good example of how parenting practices can mediate the effects of contextual variables on child adjustment. When the principles of the model are applied to pediatric cancer in families, it

becomes possible to illustrate how a sibling's individual adjustment (i.e., self-concept, thoughts about his/her future, relationships/socialization, and affect and emotional regulation) can be affected by a traumatic family event such as a life-threatening illness. It has been noted that several variables may play an indirect part in the influence of cancer on siblings (i.e., parental marital relationship, parental emotional state, financial status, and outside social support). It has also been noted that several parenting factors (i.e., parental involvement, monitoring, availability, discipline, coping, and interaction with family members) can protect the child from the impact of pediatric cancer, and therefore, limit the negative responses reported by siblings in the literature. For the current investigation, it is important to consider these family factors in the attempt to understand what aspects of the cancer experience are still salient to siblings years after their brother or sister was diagnosed with cancer.

When combining the significance of parental/familial factors to the influence of contextual factors on individual sibling adjustment to cancer, predicting adjustment outcomes becomes even more complex. The discussion now turns to the adjustment difficulties noted in literature in siblings of pediatric cancer patients.

Adjustment Difficulties in Siblings of Pediatric Cancer Patients

Overview

As we have seen from reviewing the literature on family functioning and pediatric cancer, it is not uncommon for siblings to become a peripheral, rather than central, focus in a family when a child is diagnosed with cancer. As parents strive to care for the ill child, along with maintaining financial means, household tasks, and their own psychological functioning, siblings are often left with decreased attention. As stated

above, much of the research focusing on psychosocial effects of pediatric cancer in siblings has mirrored this phenomenon. Specifically, siblings have either been ignored, or used as a control group to make comparisons with the “target,” ill child. Researchers in pediatric oncology started to study siblings more directly when they began to notice that siblings were functioning at the same (or worse) level than the patients themselves. For example, as mentioned earlier, Spinetta and Deasy-Spinetta (1981) conducted a three year investigation of 120 families of children newly diagnosed with cancer. Although the primary focus of the study was on the effects of cancer on the pediatric patients, the authors also included the child’s parents and siblings (age groups 4-6, 6-12, 13-18) in the analyses due to the fact that the child is dependent on significant others in his/her environment for support. In general, results indicated that the children with cancer were less well adjusted than controls (as measured by several standardized instruments and projective techniques), and the siblings fared the same or worse than the children with cancer on a number of criterion measures including overall emotional adjustment (ages 6-12), self-concept (ages 4-6), perceived parental distance (ages 4-6, 6-12), and higher family conflict (ages 13-18).

Similarly, Cairns et al. (1979) investigated 71 children treated for cancer and their families. Results indicated that siblings displayed higher scores on 12 out of 14 content categories as measured by the Thematic Apperception Test (e.g., anxiety, depression, mood lability, dependence, etc). In addition, on a measure of family relations, results indicated that siblings displayed more distress than the patients in areas such as expressing negative emotions to family members and perceiving parents as overprotective and overindulgent of the sick child.

Finally, Carr-Gregg, White, O’Gorman-Hughes, and Vowels (1985) compared the self-concept of three groups of pediatric cancer patients (i.e., leukemia, bone tumors, other solid tumors), their siblings, and a group of healthy children. Using the Piers-Harris Children’s Self Concept Scale, results indicated that, not only did the siblings have a significantly lower overall self-concept than the control children, but they also scored lower than all three groups of pediatric cancer patients.

When researchers found adjustment difficulties among siblings that were similar to the problems experienced by the cancer patients, siblings started to become more of a central focus in pediatric oncology research. However, when researchers began to design studies to assess effects of the cancer experience on siblings, many critical methodological issues were ignored in the design of their studies. For example, important methodological issues to consider when designing studies that assess effects of pediatric cancer on siblings include (a) whether to assess effects during the patient’s treatment or years after treatment has ended (i.e., short versus long-term effects), (b) whether to assess effects using standardized instruments and conventional quantitative comparison methods (e.g., mean differences), or using more open-ended interviews and questionnaires that are analyzed by looking for themes and patterns (i.e., quantitative versus qualitative research designs), (c) whether to use parental report to assess sibling effects, self-report elicited from the siblings themselves, or a combination of both, (d) whether to evaluate a wide or narrow age group, and (e) whether to assess siblings of deceased or living patients. Before reviewing the literature on adjustment difficulties found in siblings of pediatric cancer patients, each of these methodological issues will be discussed.

Methodological Issues

Short versus long-term effects. The majority of studies assessing sibling adjustment to pediatric cancer focus primarily on short-term effects (i.e., either during the initial phases of treatment or within the first year of remission). However, it has been suggested that siblings of pediatric cancer patients may be at-risk for long-term psychosocial problems as well (Cairns et al., 1979; Powazek, Payne, Goff, Paulson, & Stagner, 1980; Spinetta, 1981). From what has been described in the previous section concerning effects of pediatric cancer on the family unit, it seems reasonable to assume that difficulties in siblings noted could continue for many years, especially if the adjustment problems relating to family changes and the ill child's treatment are not addressed. If researchers could identify factors associated with difficult adjustment in siblings of long-term survivors, these factors could be given more attention in the initial phases of treatment and remission (Sloper & While, 1996).

Assessing long-term effects, however, poses more difficulty and threats to validity than the study of short-term effects. First, there is the issue of subject accessibility. Specifically, the majority of investigations in the area of pediatric oncology are based in large treatment centers where patients (and therefore siblings) are receiving treatment or attending follow-up care in the clinic. Samples of siblings are much more likely to be available while their brother or sister is receiving treatment, but hard to obtain when treatment has ended and families return to their homes.

Second, finding instruments that assess long-term effects of pediatric cancer can be problematic. As to be discussed later, much of the sibling research has used standardized instruments that assess behavioral and emotional difficulties. These instruments may not

be sensitive enough to detect the more mild adjustment issues that are likely to characterize siblings of long-term survivors, and are unlikely to detect cancer effects in siblings which are not pathological.

Unfortunately, although the short and long-term effects of cancer on siblings are likely to be different, many studies combine both groups in their analyses (e.g., Barbarin et al., 1995; Dolgin et al., 1997; Sahler et al., 1994; Sargent et al., 1995). This practice makes it difficult to separate out short and long-term effects, and makes estimating the severity of long-term effects or describing the course of adaptation to cancer difficult.

Quantitative versus qualitative. A second methodological issue in studies assessing sibling adjustment to pediatric cancer is the quantitative/qualitative debate. Although the issue of using qualitative research methods will be reviewed in greater detail in a subsequent section, a brief discussion is appropriate. Researchers utilizing quantitative methods gather information via rating scales and standardized questionnaires which are typically designed to assess child psychopathology. Although results from these instruments allow for the use of statistical techniques to compare mean differences between groups (as opposed to less standardized measures), and may be useful in determining whether pediatric cancer increases the prevalence of various disorders, rating scales designed to measure psychopathology may miss mild adjustment difficulties that may not necessarily be pathological, but simply different. When examining sibling adjustment of long-term survivors of cancer, effects are most likely to be mild and diverse. Therefore, utilizing a method that has the advantage of detecting subtleties may be more beneficial. An example of detecting more subtle behavior, or behavior that is more transient, is found in Chesler et al. (1991). Specifically, these authors interviewed 21

siblings (ages 10-21) of children with cancer about the effects the cancer experience on their lives. Examples of major themes that reflected more mild adjustment difficulty included (a) worry and distress about the patient's pain and social ramifications of the illness (some siblings worried so much that they had a difficult time concentrating in school), (b) changes in home life (e.g., siblings reported sadness about the home atmosphere being disrupted, parents preoccupation with the sick child and decreased physical and emotional attention for the siblings, and changes in responsibilities at home), and (c) differential treatment from parents (e.g., siblings reported feeling angry and resentment about their perceptions of inequality and unfairness).

Over the past several years, there has been an increasing appreciation for the use of qualitative methods as a research strategy (Barbarin et al., 1995; Brett & Davies, 1988; Kramer, 1984; McKeever, 1983). Through the use of qualitative techniques, such as interviews, researchers are able to gather rich, detailed information from the subjects themselves that can provide the meaning they attach to events in their lives. Due to limited studies investigating long-term effects of pediatric cancer on siblings, and, consequently insufficient knowledge and understanding of the topic, the use of qualitative methods seems highly appropriate when the study focus is long-term (vs. short-term) sibling adjustment.

Parental versus self-report. Another methodological issue in assessing effects of cancer on sibling adjustment is the use of parental report, self-report, or combined approaches in data collection. While parental data are important, interesting, and helpful, it may be less appropriate to rely strictly on the observations and interpretations of parents if the object of the research is to understand the impact of cancer on sibling adjustment. It

has been found that some problem behaviors may not be detected as readily by a parent as they would be by self-report. For example, Achenbach, McConaughy, and Howell (1987), found an average .25 correlation between parent and self-report in 11 studies they reviewed relating to the differences between informants in the report of problem behaviors.

According to Edelbrock, Costello, Dulcan, Conover, and Kalas (1986), parents and children agree least often about internalizing feelings, such as anxiety and depression, than behaviors that are more easily observable such as aggression and delinquency. To illustrate, Breslau and Prabucki (1987) (noted above) did not find any evidence of depression in siblings reported by parents, however, when siblings were also administered an interview protocol, depressive symptomology was clearly noted. Similarly, Menke (1987), in a study assessing the concerns of siblings of children with chronic illness (including cancer), found a significant difference between parents and siblings perceptions of sibling concerns. Specifically, this author found that while only 11% of the siblings stated they had no concerns related to their sick sibling, 35% of the parents stated the siblings had no concerns about the sick child. In addition, for the parents who did state that the siblings had concerns about the ill child, results indicated that these parents and siblings differed in their interpretations of the nature of the concerns.

Finally, in a study assessing effects of pediatric cancer patients, Walker (1988) found that 44% of the parents and siblings differed on accounts of sibling coping behavior. In spite of the differences noted between parental and sibling reports, several investigators in the sibling oncology literature used parents as the only means of collecting data on

sibling adjustment (Barbarin et al., 1995; Cohen et al., 1994; Dolgin et al., 1997; Horwitz & Kazak, 1990; Peck, 1979; Schuler et al., 1985).

On the other hand, collecting data via self-report can also be troublesome. For example, many self-report inventories include items that are clearly recognized as more “socially acceptable” than other responses. Individuals responding to these items may be motivated to “fake good” or choose answers that produce a more favorable impression of themselves. Conversely, there may be some individuals who choose to respond in an unfavorable light (i.e., malingering) in deliberate pursuit of a certain goal (e.g., attention, sympathy, mental health services, etc.) (Anastasi, 1988). The unreliability of both self and parent reports makes it important that multiple data collection methods be used, and that results be interpreted cautiously.

Collecting data via the use of structured interviews with subjects also involves factors that must be considered before results can be accurately interpreted. For example, when evaluating the responses of the subject, it is important to consider the subject’s age and developmental level (discussed earlier), intellectual ability, and cultural and other factors that may influence how a subject responds (Sattler, 1998). In addition to the biases mentioned above (i.e., social desirability, malingering), there are other potential sources of error associated with self-report in structured interviews. Examples of these factors include the subject’s (a) attitude (subjects who are angry and uncooperative, or feel pressure to provide certain responses will most likely not contribute the most useful information), (b) language (subjects may have difficulty finding the correct words to describe their thoughts and feelings, and may misuse words unintentionally), (c) affect (subject’s anxiety over the interview may hinder their ability to provide accurate

responses, and (d) behavior (subjects may behave differently in the interview than in their normal lives).

Studies that focus on long-term effects may also be weakened by the need to rely upon participants' memory of events. This can become especially problematic when interviewing children about certain events, perceptions, and feelings that occurred when they were very young. For example, according to Ornstein, Larus, and Clubb (1991), children under five years of age have less efficient information processing skills, such as speed of encoding, which can greatly influence the amount and accuracy of recall at a later date. In addition, these authors state that children will be better able to recall events shortly after they occur due to the fact that children's memories are likely to fade more rapidly than adults. Furthermore, after a delay in time, it is not uncommon for individuals to unconsciously distort their interpretation of an event due to weakened memory traces. As memory fades over time, individuals may exaggerate or minimize the significance of events, as well as interpret their own behavior in a manner that is consistent with the current image they hold of themselves (Sattler, 1998). According to Lindsay and Read (1994), individuals may believe that suggestions or imagined events are actually real events, and can relate these events in a vivid and detailed manner that appears convincing to themselves and to others. Clearly, the effect of time on recall is important to understand when assessing the accuracy of children's reports of events, and the accuracy of their reports of how these events have affected them. Thus, siblings' reports of their interpretations concerning their long-term adjustment are important, but may not be considered "factual" interpretations, undistorted by intervening events, or the siblings' account of events and their impact.

Wide versus narrow age range. Many researchers assessing effects of pediatric cancer in siblings have incorporated a wide age range of subjects in their analyses. Some of these researchers tested the effects of age on various outcomes (Cairns et al., 1979; Cohen et al., 1994; Haversman & Eiser, 1994, Koch-Hattem, 1986; Sahler et al., 1994; Sargent et al., 1995; Sloper & While, 1996), while others used a wide age range, but did not test for age differences (Barbarin et al., 1995, Chesler et al., 1991; Dolgin et al., 1997; Evans, Stevens, Cushway, & Houghton, 1992; Gogan et al., 1977; Koch, 1985; Kramer, 1984). Still, other researchers narrowed the age range in their studies to include only a single age group (Bendor, 1990; Horwitz & Kazak, 1990; Iles, 1979; Martinson et al., 1990; Shapiro & Brack, 1994; Walker, 1988).

Whether one chooses to evaluate a wide age range of subjects, or decides to focus on a more narrow age group, understanding children's intellectual and psychosocial functioning within a developmental framework is crucial, especially when assessing the effects on children who have to cope with a traumatic event in their family such as cancer.

Surviving versus deceased sibling. The last methodological issue to be discussed is the issue of whether to include siblings of children who have survived cancer or siblings of children who have died. The majority of researchers in this area have chosen one or the other, however, there have been a few studies that included siblings in both groups. For example, Martinson and colleagues (1990) followed 40 families with children diagnosed with cancer for five years. At the end of the five year period, siblings evaluated included nine siblings of cancer survivors and seven siblings of children who had died. Similarities of the two groups of siblings included feelings of loneliness and sadness, especially when their sibling was hospitalized. Differences between siblings of living and deceased

children included the language that was used to talk about the illness (i.e., siblings of deceased children tended not to use the word “cancer” in describing illness), the fears about contracting a life-threatening illness (siblings of deceased children displayed more concern about their own health), and the safety of the sibling’s parents (siblings of deceased children worried about additional loss in the family).

There have been numerous investigations that have documented the reactions of children who have lost a sibling to cancer (e.g., Cain, Fast, & Erickson, 1964; Blinder, 1972; Binger et al., 1969; Davies, 1991; Hogan, 1988; Hogan & Balk, 1990; Lauer, Mulhern, Bohne, & Camitta, 1985). Among the reactions observed in siblings of dying and deceased children include feelings of envy, guilt, anxiety, death phobias, depression, somatic symptoms, and distorted concepts of illness and death. Although these responses may be very similar to what siblings of surviving children endure (discussed below), it is reasonable to assume that the experiences between the two groups of siblings will vary, and should be evaluated separately. Specifically, it can be presumed that a sibling who is faced with adjusting to new family demands and living with a brother or sister with a chronic illness will undergo different challenges than a sibling who is faced with adjusting to the loss of a brother or sister.

In summary, several methodological issues regarding assessing the effects of pediatric cancer in siblings have been discussed. These issues of evaluating short versus long-term effects, employing quantitative versus qualitative methods, using one or more informants, including a wide or narrow age range, and assessing siblings of living or deceased children are all important in considering how pediatric cancer affects siblings’ psychosocial adjustment. The review will now turn to a discussion of the behavioral and

emotional effects of pediatric cancer on siblings that have been noted in the literature. Due to the scarcity of methodologically sound investigations in the area of sibling oncology, a brief review of the effects of chronic illness (general) in siblings is warranted. The review will then turn to a discussion of behavioral and emotional outcomes noted in siblings of pediatric cancer patients, beginning with short-term effects (i.e., general, anger/envy/behavioral, grief/depression, anxiety, somatization) and then discussing what long-term effects have been found. The review will conclude with reviews on the short-term social adjustment difficulties, academic problems, and positive outcomes reported in siblings of cancer patients.

Behavioral and Emotional Outcomes for Siblings/Chronic Illness Literature

It has been estimated that 10% of children in the United States have some type of chronic illness (Perrin, 1985). How families with children who have a chronic illness cope with and adapt to the illness-related stress has been the focus of numerous investigations. According to a survey of life events investigated by Coddington (1972), a sibling illness which requires hospitalization ranked among the most stressful of life events in a representative sample of 3,620 children ranging in age from pre-school to high school.

Studies that have found emotional and behavioral disturbance among siblings have included investigations assessing a variety of pediatric chronic illnesses and disabilities (Breslau Weitzman, & Messenger, 1981; Menke, 1987; Tritt & Esses, 1988). For example, behavior problems (i.e., externalizing behaviors) were noted by Breslau et al. (1981) and Breslau and Prabucki (1987). Specifically, in a five year longitudinal study of 192 siblings of chronically ill children (i.e., cerebral palsy, cystic fibrosis, myelodysplasia,

multiple handicaps) and 284 control siblings, siblings of chronically ill children were rated significantly higher than controls on the total behavior problem scale, conflict with parents, fighting, and delinquency. In addition, these siblings reported a higher incidence of oppositional behaviors (e.g., breaking minor rules, arguing, disobedience) than controls. Although the results documented effects of chronic illness on sibling affective and behavioral adjustment, it is important to note that no distinctions were made between the various illnesses studied.

Similarly, Ferrari (1984) investigated sibling adjustment of children with pervasive developmental disorder, juvenile onset diabetes, and healthy children ($N = 48$). Siblings of the diabetic children were reported by parents as displaying the highest level of behavior problems on the Child Behavior Checklist (1 SD above the mean). Externalizing problems were the most significant compared to the two other sibling groups. A significant portion of the diabetic siblings reported more somatic complaints than the other two groups, as well as rated themselves as the least happy in the family.

Internalizing difficulties have also been noted in siblings of chronically ill children. For example, Lavigne and Ryan (1979) compared siblings (ages 3-13) of pediatric cardiology, hematology, and plastic surgery patients to siblings of healthy children ($N = 203$), and found that the siblings of the chronically ill children were significantly more likely to display symptoms of depression and withdrawal than the comparison group. Furthermore, the authors stated that, although all illness groups scored significantly higher in these areas, the siblings of plastic surgery patients displayed the highest level of severity. The authors attributed this finding to the visibility of the

illness in plastic surgery patients, which can cause others to respond differently to the child and also siblings.

Similarly, Tritt and Esses (1988) evaluated 27 siblings of children with a chronic illness (i.e., juvenile onset diabetes, juvenile rheumatoid arthritis, and gastrointestinal problems) and 27 siblings of healthy children. Results from the administration of several standardized instruments indicated that the siblings of chronically ill children were perceived by parents as having significantly higher internalizing problems than the control group. In addition, the siblings of chronically ill children reported they were the least happy of all family members. It is important to note that these authors did not separate illness groups for analysis either.

Finally, in the Ontario Child Health Study, which was an investigation of the emotional and behavioral difficulties among over 3,000 siblings of children having one of 15 chronic illnesses (including cancer) and controls, Cadman, Boyle, and Offord (1988) found that the siblings of the chronically ill children were at an increased risk for internalizing disorders (e.g., depression, anxiety), but not externalizing problems.

There have been researchers who did not find differences in problem behaviors between siblings of chronically ill children and control siblings. These researchers include Vance, Fazan, Satterwhite, and Pless (1980), in their study of siblings of children with nephrosis; Dyson (1989), who investigated siblings of mentally disabled children; and Lavigne & Ryan (1979), who did not find differences in aggression in a sample of siblings of children with hematology, cardiology, and plastic surgery patients.

Discrepancies noted in the literature on the effects of chronic illness on siblings suggest that the effects of the illness may be specific to the illness and disease process

(Tew & Laurence, 1973). Each illness differs on a variety of characteristics in terms of onset, symptomology, chronicity, severity, prognosis, degree of incapacitation, visibility, and transmission. Even with mixed results found in the literature, it seems reasonable to state that chronic illness in the family is an ongoing stressor, which, when combined with other family variables (e.g., parental and ecological variables described in the previous section), can increase the risk of adjustment difficulties in some healthy siblings.

A chronic illness such as cancer is likely to cause problems in adjustment for healthy siblings due to the “acuteness” of the illness. Specifically, complications in treatment, invasive painful procedures, and unpredictable prognosis make cancer life-threatening and very frightening for all family members, including siblings. Much has been written on the adjustment difficulties reported in siblings of pediatric cancer, however, as stated above, there are many methodological problems associated with several of these studies. Many of these problems and methodological issues exist in studies that assess long-term effects of cancer on siblings, which are likely due to the difficulties noted above (i.e., patient accessibility, selection of instrumentation) As a result of these difficulties, residual effects of pediatric cancer on siblings in the literature is lacking, thus, further justifying the evaluation of long-term effects in the current study. Before discussing what has been noted in the literature on long-term effects on siblings, behavioral and emotional short-term effects will be reviewed.

Behavioral and Emotional Outcomes for Siblings/Cancer Literature

Short-term effects/general. A number of researchers have noted various behavioral and emotional responses in siblings to pediatric cancer. As noted in previous sections, when a child is diagnosed with cancer, the family unit is disrupted as the child

must undergo painful treatment which is likely to cause separation of family members, changes in family roles and responsibilities, overindulgence of the ill child, and decreased parental emotional and physical attention for the healthy siblings. Feelings of guilt, loneliness, jealousy, rejection, anger, depression, and anxiety were among the emotional symptoms of distress reported in siblings of cancer patients in several studies (Balk, 1983; Barbarin et al., 1995; Bender, 1990; Cairns et al., 1979; Carpenter & Sahler, 1991; Chesler et al., 1991; Evans et al., 1992; Havermans & Eiser, 1994; Iles, 1979; Kramer, 1984; Koch, 1985; Koch-Hattem, 1986; Lavigne & Ryan, 1979; Martinson et al., 1990; Sahler & Carpenter, 1987; Sargent et al., 1995; Shapiro & While, 1996; Spinetta, 1981; Walker, 1988).

For example, Sahler and colleagues (1994), in a 7-site, large-scale investigation of effects of cancer on siblings, compared 254 siblings (ages 4-18) with healthy siblings from the National Health Survey. Siblings and their parents completed various standardized instruments assessing problem behaviors, coping, and family factors. On the Behavior Problem Index, results indicated that siblings of pediatric cancer patients were two to four times more likely than a non-clinical normative sample to reach criteria for clinical disturbance. In addition, these authors stated that the presence of problems before diagnosis was likely the best predictor of problems after diagnosis, in that 77% of siblings who were reported as having difficulties in behavior, school, and health post diagnosis, had pre-existing problems. Although these authors found significant differences in problem behaviors when comparing siblings of cancer to healthy controls, the “type” of problems were not identified in the results (i.e., internalizing versus externalizing difficulties).

There are a number of studies where researchers have noted increases in sibling problem behavior after diagnosis, but failed to distinguish between internalizing and externalizing problems. For example, Schuler et al. (1985) followed 81 families for years who were all in different disease and treatment stages of cancer. Results indicated that problem behavior in siblings significantly increased from the initial diagnosis (i.e., 28%) through the progression of the illness (59%). However, not only do the authors give a poor description of types of problem behaviors noted, but they also do not indicate if the problems indicated were in the families of deceased children or survivors. Likewise, Sahler and Carpenter (1988) evaluated the effects of cancer on 82 siblings of pediatric patients. From parental report, 39% of the siblings were noted as developing problems after the diagnosis of their brother or sister, however, specific behavior or emotional problems were not indicated.

Barbarin et al. (1995), on the other hand, interviewed the parents of the 254 siblings in the same large-scale investigation and found that there was a 20% increase in problems experienced by siblings after diagnosis. Problems indicated were in the areas of general adaptation, internalizing, externalizing, social competence, academic, physical health, and conflict with family members. Of the 141 siblings who were reported as not having problems pre-diagnosis, 56% were reported by parents as experiencing difficulties after the diagnosis. Furthermore, 25% of the problems indicated were internalizing difficulties, while 18% of the problems noted fell into the externalizing category. As stated above, parental ratings, although useful, may not provide the most complete picture of a child's adjustment or emotional functioning.

Short-term effects/anger, envy, and behavior problems. Several investigators have noted that among the emotions expressed by siblings of cancer patients included feelings of anger and jealousy (Barbarin et al., 1995; Carpenter & Sahler, 1991; Iles, 1979; Schuler et al., 1985). Specifically, Kramer (1984) interviewed 11 siblings about their experiences with pediatric cancer. The author found that, among the themes generated, many of the siblings interviewed resented the over-protectiveness and over-indulgence of the sick child by parents. As stated earlier, siblings were noted to complain to their parents that their brother or sister never receives discipline for misbehavior, and can often stay home from school when feeling ill. The author noted that many of these siblings responded to the differential treatment with feelings of anger, confusion, and frustration. In addition, the author noted that the sibling rivalry reported by the siblings, subsequent to the feelings of anger and jealousy, became intensified and in some instances, led to hostility and increased competitiveness.

Behavior problems in siblings of pediatric cancer patients have been noted in the literature. For example, Sloper and While (1996) evaluated the adjustment in 99 siblings (ages 8-16) of pediatric cancer patients (six months after diagnosis) using a variety of standardized instruments. Results from the Child Behavior Checklist completed by parents indicated that in general, 28% of the siblings had scored in the borderline to clinical range of emotional and behavioral disturbance. In addition, 86% of these siblings displayed problems (i.e., 42% externalizing problems, 25% internalizing problems, 33% mixed externalizing/internalizing problems) since their brother or sister was diagnosed. Again, it is important to note that since only parents completed the instrument, results may not completely reflect the siblings' difficulties.

Cohen et al. (1994) also assessed sibling adjustment to pediatric cancer using the Child Behavior Checklist (CBCL) as one of the primary instruments in their investigation. Parents of 129 siblings (ages 4-16) of cancer patients diagnosed less than four years before the study completed rating scales on the siblings' behavior. Compared to the normative data on the CBCL, siblings of cancer patients were reported by parents as being one standard deviation above the mean on externalizing behaviors (28% of siblings) and internalizing behaviors (33% of siblings). Although the authors relied solely on parental report, these results suggest that siblings of pediatric cancer patients are at an increased risk for both internalizing and externalizing problems.

There have also been qualitative studies that have found behavior problems in siblings of pediatric cancer patients. For example, Walker (1988) interviewed 26 siblings (ages 7-11) and their parents to assess adjustment difficulties experienced by the siblings of cancer patients. Although many projective techniques were also used as means for data collection (e.g., drawings, story telling, sentence completion, etc.), results from the parental interviews suggested that, in general, 69% of the siblings had one or more behavioral, affective, or social problem. Specifically, physical aggression was reported in 34% of siblings, verbal aggression was reported in 61% of siblings, emotional lability was noted in 46% of siblings, and attention seeking behaviors were noted in 27% of siblings. Similarly, Bendor (1990) assessed the effects of cancer on 5 siblings (ages 9-12) and 4 siblings (ages 14-19) in a group program that lasted eight weeks. Content from the group sessions were analyzed and results indicated that 3 out of the 5 younger siblings displayed physical aggression either at home or school, and nearly all of them expressed increased jealousy regarding the differential treatment of the sick sibling. Obviously, results from

this study need to be interpreted with caution considering the sample size in both groups. Additionally, although the results from the previous two studies are more descriptive in nature, they do indicate that siblings of cancer patients do appear to have some difficulty adjusting to the changes experienced when their brother or sister is being treated for cancer.

In sum, it has been reported that some siblings do experience feelings of jealousy, anger, and resentment towards their parents and sick sibling for the perceived differential treatment that results after a diagnosis of cancer. Unfortunately, intense feelings of anger may lead to feelings of guilt, resulting in the healthy sibling being ashamed over their feelings of anger or thinking bad thoughts regarding their brother or sister, or even about feeling healthy themselves. According to Kramer (1981), this cycle of feelings may then provoke a variety of maladaptive behaviors in the healthy sibling. If the sibling does not have effective coping mechanisms to handle the mixture of emotions, a more involved mood disturbance may result.

Short-term effects/grief and depression. Grief responses are reported to be common among siblings of pediatric cancer patients, but vary in terms of the amount communicated to parents, peer, clinicians, or even the sick child. In an attempt to organize their understanding of the illness and prognosis, some siblings ask endless questions, while others are virtually silent. It is not uncommon for some siblings to initially display periods of sadness, but attempt to continue with their life in their usual manner. Their grief responses may include “adult-like” behavior such as verbal expression of grief, while others express their sadness through play (Lavigne, 1980). However, in some cases, “sadness” may turn into withdrawal, mood lability, sleep and

appetite disturbance, and/or thoughts of suicide. There has been evidence in the literature of siblings of pediatric cancer patients exhibiting symptoms of depression (Bendor, 1990; Carpenter & Sahler, 1991; Evans, 1992; Kramer, 1984; Koch, 1985; Martinson et al., 1990; Sloper & While, 1996; Walker, 1988). For example, Barbarin et al. (1995), investigated adjustment in 254 siblings (ages 4-18) on a number of domains including internalizing behaviors (i.e., depression, withdrawal, etc.). These authors found that while approximately 7.5% of the siblings in the sample were noted as exhibiting significant symptoms of internalizing behavior before the diagnosis, the percentage rose to 14% of the siblings experiencing internalizing symptoms. Specific symptoms reported included increased moodiness, holding emotions inside, feeling inferior, and thoughts about death and suicide. Even though results were calculated from parental report only, the fact that the internalizing behaviors increased after diagnosis is noteworthy.

Short-term effects/anxiety and fear of death. In general, it has been stated above that siblings may experience more anxiety and other internalizing behaviors than the patients themselves. Cairns et al. (1979) found that siblings of pediatric cancer patients had higher scores than the patients on 12 out of 14 scales (including anxiety and depression) as measured by the Thematic Apperception Test, indicating more disturbance. Similarly, Spinetta and Deasy-Spinetta (1988) indicated that siblings (ages 6-12) scored at higher maladaptive levels of anxiety and depression than the patients on measures of the Roberts Apperception Test.

Fears about death, either their own or their sibling's, is another major theme observed in the literature. According to Sourkes (1980), the fear of becoming ill with cancer is very prevalent among siblings of pediatric cancer patients. What is typically

frightening for the healthy sibling is that they often identify with and see many similarities between themselves and their sibling. They come to understand that past experiences that affect one child often affect another, and it is only a matter of extension for the siblings to believe that an illness that occurs in one child could easily befall the sibling. This logic, according to the author, is especially true when the healthy sibling cannot find a reasonable cause for their sibling's illness, and then feels that this randomness of events could just as likely happen to them.

One particular source of anxiety and distress for the healthy sibling is the physical changes he or she observes in their brother or sister as a result of the intrusive treatment protocols (e.g., hair loss, weight loss/gain, possible amputation, etc.). Kramer (1981) states that witnessing these physical changes can drastically increase the healthy sibling's anxiety level and threaten the healthy sibling's own physical and emotional well-being, resulting in fears of becoming ill themselves. The author also contends that the need to be "normal" may be so great that healthy siblings worry about their family appearing "different" and, subsequently, cause them embarrassment or shame over their sick brother or sister.

In addition, Lavigne (1980) found that phobias pertaining to death were common. Several siblings in the study stated that they feared they might die at the same time or manner as their sick brother or sister. The author postulated that these feelings were thought to result from parental over-protectiveness of the sick sibling, rather than from the sick sibling directly. In addition, Bendor (1990), in a qualitative study of 10 siblings noted that one of the major sources of anxiety in both age groups (8-13, 14-19) was the fear of becoming ill themselves. However, in the older age group, the fear was more

related to the sibling passing an infection onto the sick child than it was to the healthy sibling dying.

Siblings worrying about the prognosis of the sick sibling and fearing relapse in their brother or sister has also been noted in the literature (Bendor, 1990; Havermans & Eiser, 1994; Sargent et al., 1995). For example, Chesler et al. (1991), in a qualitative analysis of sibling short-term effects, found that the 21 siblings in the study universally expressed worry about the patient's illness and possibility of death. These authors stated that some of the siblings became so concerned with their sibling's illness that they were unable to concentrate in school. Similarly, Koch (1985) found that 22 out of 33 siblings described their concern and fear about their brother or sister's future, and exhibited sorrow about their sibling's suffering in ways including sympathy and/or expressing a desire to accept the pain in their sibling's place.

Short-term effects/somatization. There is evidence in the literature of psychophysiological responses precipitated by either a sibling's death or illness, which are manifested in variety of somatic complaints including enuresis, headaches, stomach aches, and changes in sleep and appetite patterns (Cairns et al., 1979; Carpenter & Sahler, 1991; Sahler & Carpenter, 1987, Walker, 1988). For example, Blinder (1972) found that siblings often had somatic complaints which mimicked those of their deceased brother or sister. In addition, Cain et al. (1964) found 40% of siblings of pediatric cancer patients identified with their sick brother or sister, which resulted in either immediate or prolonged exhibition of their dying sibling's prominent symptoms. Finally, Koch (1985) interviewed siblings of cancer patients and found that one of the principal themes that emerged from the data included health problems following the diagnosis of cancer. Specifically, 19 out

of 25 siblings displayed the pattern of exhibiting physical symptoms after their brother or sister was diagnosed, including headaches and stomachaches, as well as health problems requiring medical attention such as hepatitis, multiple knee injuries, and a car accident that resulted in the death of one sibling.

Long-term effects. As stated above, there are few studies that focus solely on long-term effects of cancer on siblings. Some researchers, however, include long-term survivors in their samples but then fail to distinguish between the effects in siblings of short-term and long-term survivors. Specifically, researchers such as Barbarin et al. (1995), Dolgin et al. (1997), Sahler et al. (1994), and Sargent et al. (1995) all made use of a sample consisting of 254 siblings who had a brother or sister diagnosed with cancer between six months to four years after diagnosis. Results do not indicate whether effects found were characteristic of siblings of short or long-term survivors.

Conversely, some authors do differentiate between short and long-term effects in their samples, however, results are typically based on assumptions. For example, Kramer (1984) conducted interviews with 11 children of pediatric cancer patients (ages 6-16). Although the children with cancer were between 8 and 66 months post diagnosis, this author stated that there was only “anecdotal” evidence regarding lingering effects in the siblings of long-term survivors. Specifically, these siblings reported continued favoritism on the part of the ill child (which resulted in resentment), as well as ongoing concern about their brother or sister relapsing or having residual effects from the treatment. It is important to note that the number of siblings of long-term survivors in this study is not reported.

There have been a few studies that have focused solely on longer term effects of pediatric cancer on siblings, however, methodology problems resulted. For example, Gogan et al. (1977) interviewed 13 siblings of long-term survivors of pediatric cancer. Results did not indicate that the cancer experience had a significant impact on the siblings, nor that the siblings felt guilty or abandoned as often noted in the literature. These data must be interpreted cautiously in light of the fact that 10 of the 13 siblings interviewed had been five years old or younger at the time of diagnosis, and that the average length of time from diagnosis to time of interview was 13.5 years.

Similarly, Peck (1979) examined family members of pediatric cancer patients who had been in remission 4 – 13 years. Although 20 siblings were part of the investigation, they were not interviewed directly. However, according to parental report, feelings of jealousy were most noteworthy. Other long-term problems reported included feeling rejected by parents, school difficulties, and somatic complaints. It is important to note, however, that this study was primarily descriptive in nature, had a small sample size of siblings, and was based solely on parental report. In addition, results do not indicate how many of the siblings had each problem identified.

Finally, Schuler et al. (1985) conducted a longitudinal study of 81 families having a child diagnosed with cancer. Although siblings were not a central focus of the investigation, parents reported on their adjustment as part of an interview protocol. Results indicated that 35% of the siblings had problems that were, for the most part, temporary and occurred at or near the time of diagnosis. However, the majority of the siblings were described as having problems (especially anxiety) that remained high even during the later stages of their sibling's illness. These results need to be interpreted

cautiously due to the fact that the sample consisted both of families whose child had survived, and families whose child was deceased. Also, due to the fact that the study was not solely focused on siblings, the description of the sibling sample was very poor (e.g., age, time since diagnosis, etc.)

Due to the shortage of studies conducted on the long-term effects of pediatric cancer on siblings, the inadequacy of long-term results reported, and the assumptions made regarding residual effects on siblings of cancer patients, it is clear that there is much ambiguity in determining how cancer affects siblings years after diagnosis and treatment. In order to begin to understand long-term effects of cancer on siblings, the current study will focus on siblings of children who have been diagnosed with cancer at least three years before the investigation. Understanding siblings' interpretations of the cancer experience and what aspects of the experience are still salient years after diagnosis and treatment may be helpful in promoting healthy coping strategies during the early phases of the illness.

In short, the literature on siblings of pediatric cancer patients reveals that most siblings show a wide range of adjustment difficulties which may even persist into remission. Adjustment problems, primarily in studies assessing short-term effects have included behavioral and emotional reactions such as aggression, acting out, grief, anxiety, anger, guilt, and somatic complaints. However, there are a handful of studies which found no significant differences between siblings of cancer patients and siblings of healthy children. These studies are briefly described here.

Horowitz and Kazak (1990) evaluated 25 siblings, ages three to six years old, and concluded that these young siblings of cancer patients did not show any significant differences in behavioral problems compared to siblings of healthy children. However,

these authors assessed only the parents of the preschool siblings on a standardized instrument that is primarily designed to assess clinical levels of disturbance. It is likely that this instrument did not detect the more subtle adjustment difficulties.

Similarly, in a cross-cultural study, Dolgin et al. (1997) compared Israeli siblings of pediatric cancer patients to a group of matched Israeli healthy siblings, as well as to an American sample of siblings of pediatric cancer patients. Results indicated that the Israeli siblings of cancer patients scored significantly lower than the control group of Israeli healthy siblings, indicating fewer behavior problems. In addition, the scores on the CBCL for the Israeli and American group of siblings of pediatric cancer patients yielded non-significant results in the areas of externalizing and internalizing behaviors. Results, however, should be interpreted cautiously due to the fact that the comparison of Israeli and American siblings consisted of only 35 subjects each. Likewise, Evans et al. (1992) evaluated the adjustment of 16 siblings (ages 6-16) of pediatric cancer patients. Results indicated that mean scores on the CBCL were within normal limits on total problem behaviors. Again, the study consisted of a very small sample size, which should be considered when interpreting results.

Finally, Gogan et al. (1977) interviewed 13 siblings of pediatric cancer about their reactions following their brother or sister's diagnosis. Siblings reported that the diagnosis of cancer had no significant impact on them, nor did they experience feelings of guilt or abandonment by their parents. As noted earlier, these results must be interpreted with caution due to methodological problems.

Again, it is important to note that these researchers who did not find significant difficulties in the adjustment of siblings to pediatric cancer either used primarily

quantitative measures, in which standardized instruments may not have been sensitive enough to detect milder adjustment issues, or used designs that were not methodologically sound.

In summary, results of controlled studies suggest that pediatric cancer is a stressor which may contribute to an increased risk of psychological maladjustment in some healthy siblings. Along with emotional instability and behavioral difficulties described above, changes in siblings' interpersonal relationships are typically an area of concern after a brother or sister receives treatment for cancer.

Social Adjustment

Short-term effects. It has been noted in the literature that siblings of pediatric cancer patients often encounter perceived changes in their social relationships as a result of the cancer experience (Blinder, 1972; Brett & Davies, 1988; Hogan, 1988; Hogan & Balk, 1990; Martinson et al., 1990; Sourkes, 1980; Walker, 1988). One of the primary themes in the literature relates to siblings feeling tension in their relationships with peers due to not being able to communicate their perceptions, fears, and attitudes pertaining to their sibling's cancer. For example, Shapiro and Brack (1994) assessed peer relationships in siblings (ages 7-10) of pediatric cancer patients and found that many of the siblings did not share details about their brother or sister's illness with peers (i.e., 66%). These siblings reported that they did not feel comfortable talking about the illness and associated treatment due to concern regarding their peers' reactions. This finding is important when considering that peers may be one of the primary means of support for siblings whose parents are physically and emotionally occupied with the ill child. These findings need to be interpreted with caution due to the small sample size ($N = 9$ parents and 6 siblings).

Similarly, Havermans and Eiser (1994) interviewed 21 healthy siblings about their experiences when a brother or sister is diagnosed with cancer. A major theme in the study was the perception that the siblings' interpersonal relationships with others (including peers) were negatively affected by the cancer experience. It is also important to note that almost 20% of the sample reported no means of social support during this time. When the siblings who perceived negative changes in their relationships or felt they did not receive social support were asked to explain the reasons, some of them stated they "felt awkward talking about it" or said they "did not need anyone."

Due to increased tension in peer relationships, as well as the effects of cancer on the family, social isolation may result. As stated above, Cairns et al. (1979) evaluated siblings (ages 6-16) in 71 families who had a child with cancer and found that siblings displayed more distress than the patients in perceived social isolation, particularly in terms of being able to express negative feelings to others. These authors postulated that the sibling's reluctance to express negative emotions may have been due to a feeling of instability in the family, and the fear that anything they do or say may only make matters worse.

Bendor (1990) also found that siblings were hesitant to express emotion and felt isolated from peers in a qualitative study that evaluated a group program for siblings (ages 9-12, 14-19) of children with cancer. Specifically, this author found that siblings in both age groups reported feeling alone when attempts to connect with peers were unsuccessful. In addition, these feelings of loneliness were then compounded with decreased social interaction and restricted recreational activities outside the school due to the family's financial difficulties and need for

the sibling to help the family at home. Again, due to the small sample size of the groups, results need to be interpreted with caution.

There have been researchers who did not find any differences in social functioning among siblings of cancer patients. For example, Horwitz and Kazak (1990) compared 25 preschool siblings of cancer patients to 25 preschool siblings of healthy children and found no differences in parental ratings of social competence. Similarly, Barbarin et al. (1995) interviewed parents of 254 siblings of pediatric cancer patients about problems before and after diagnosis. Results indicated that 8% of the siblings were reported by parents as having interpersonal relationship difficulties before the diagnosis, while only 1.6% were reported as having problems in this area after diagnosis. The authors did not offer possible reasons for these findings.

Unfortunately, the school environment is typically where siblings of cancer patients feel stigmatized and experience tension in their peer relationships (Evans et al., 1992). Specifically, relationships may be strained by peers feeling awkward about the physical appearance of the sibling's brother or sister, as well as a feeling of not knowing what to say to the sibling about the illness. Iles (1979) found that four out the five siblings interviewed reported tension in the school environment due to not knowing what to say to peers about their brother or sister's physical appearance or absences.

According to Kramer (1981), classmates may often not have the words to express the sympathy and concern that they might be feeling, so they say and do nothing, which, unfortunately may leave the sibling feeling isolated, hurt, and angry. In addition, many siblings may feel torn between loyalty to their sick brother or sister and the need to avoid looking "different" to their peers, as well as to avoid the stigma associated with the illness.

Long-term effects. There have been no studies that addressed long-term social isolation or tension in siblings' interpersonal relationships, thus, making drawing conclusions regarding social functioning in siblings of long-term cancer survivors difficult. The current study focused on siblings' interpretations of changes in their relationships with their peers, parents, and sick brother or sister.

Academic Difficulties

Along with feeling stigmatized at school and, consequently, isolated from their peers, siblings may act out their feelings of anger, resentment, and fear in the school environment, which can create problems both in school behavior, as well as academic performance. Although studies of siblings of pediatric cancer patients focus primarily on behavioral, emotional, familial, and social outcomes, there is some evidence (although limited) for siblings experiencing academic difficulties as a result of the cancer experience (Iles, 1979; Martinson et al., 1990; Sourkes, 1981; Spinetta, 1981; Tiller, Ekert, & Richards, 1977). Again, due to a lack of studies that investigate the effects of pediatric cancer on academic functioning, some review of the effects of chronic illness on siblings' academic performance is warranted.

For example, Tew and Laurence (1973) compared 44 siblings of spina bifida patients to 63 siblings of healthy children (ages 2-15) on measures of school adjustment. Results, as reported by teachers, indicated that the siblings of spina bifida patients were four times more likely to display maladjustment in school than the control siblings. Unfortunately, these authors did not differentiate between the problems reported by teachers, making it unclear as to whether the school problems involved lower grades and incomplete school work, or difficulties with behavior in the classroom.

Similarly, Vance et al. (1980) compared 79 siblings of children with nephrosis to 79 siblings of healthy children. Results from teacher ratings of academic performance suggested that the siblings of nephrotic children were significantly lower than the control group in the areas of underachieving and overall school performance.

The studies that do focus on academic problems in siblings of pediatric cancer patients are primarily studies which include siblings of patients who did not survive cancer. For example, Balk (1983a) interviewed 33 adolescent siblings regarding their grief reactions following the death of their brother or sister. Effects on grades and study habits was a theme that emerged from the data. Specifically, 23 of the 33 adolescents reported that their time spent studying had declined after their sibling had died, and 16 of the adolescents interviewed stated their grades had suffered as a result of the death. Similarly, Davies (1993) reviewed several studies on children whose sibling had died from an acute illness and found that nearly one-third of the healthy siblings experienced poor school work primarily due to difficulty in concentrating. Finally, Kaplan et al. (1976) conducted one of the first studies where 40 family members were followed for three years starting at the time of diagnosis to after the patients died. Parental reports indicated that 43% of siblings were reported by parents as having school difficulties.

Shapiro and Brack (1994) conducted a study of academic functioning in siblings of pediatric cancer patients within the first year after diagnosis. These authors reported that although 60% of the parents stated the sibling had a difficult time completing homework after the diagnosis, only 17% of the siblings reported this fact. No other school problems were noted. Results of the study need to be interpreted cautiously, however, due to the small sample size of siblings ($N=6$), and the fact that the sample consisted solely of

families who lived in large urban areas, and had the resources to attend a special program, where the data were collected.

In summary, results from studies on siblings of children with cancer suggest that siblings do experience changes in the interpersonal relationships with peers, which may lead to social withdrawal, as well as possible difficulties in the school environment. Although many of the studies that report changes in the social and school areas of sibling behavior have methodological flaws associated with them, it is still reasonable to suspect that siblings of pediatric cancer patients will have changes in these areas. It is important to note that none of the studies reviewed have examined long-term social or academic difficulties in siblings of cancer patients, and therefore, were included in the current study.

In addition, although the majority of evidence cited in this review of sibling adjustment to cancer has focused on negative changes in behavior, emotion, social relationships, and academic functioning, there have been several studies that discuss aspects of the cancer experience that siblings perceive to be positive to the family as a unit, as well as to their own psychological growth (Davies, 1995). Examples of positive effects will be reviewed briefly.

Positive Outcomes

Experiencing the death of a sibling, or enduring months or years of a sibling's painful treatment for cancer, not only results in problem behaviors and difficulties with social and academic functioning, but may also lead to positive changes in the sibling's overall adjustment, both individually and in the family. The majority of positive effects noted by parents and siblings relate to siblings acting more responsible and mature, feeling more compassion for others, and attributing increased value to life (Barbarin et al., 1995;

Chesler et al., 1991; Havermans & Eiser, 1994; Sargent et al., 1995.) For example, Evans et al. (1992) evaluated 16 families of children with cancer using various parental and sibling ratings. Results indicated that siblings of pediatric cancer patients were noted to mature more quickly than their peers, which was hypothesized to be due to the cancer experience, and were reported to help out at home more frequently since their sibling's diagnosis.

Kramer (1981) also noted that the shift in household responsibilities provides opportunities for siblings' psychological growth. Specifically, this author contended that helping with chores at home teaches responsibility and self-reliance, which may help foster positive self-esteem. In addition, it has been noted that siblings perceive themselves to be better prepared to handle personal distress after experiencing cancer in their family, as well as realizing that life has many disappointments and challenges that require one to become more flexible and adaptable in order to adjust to the many difficult and rigorous changes.

According to Davies (1995), siblings of ill children may also perceive themselves as more empathic and sensitive to other's needs. Specifically, they often develop a great respect for their sick brother or sister for all they have endured, and as a result, may acquire a unique capacity for compassion, empathy, and cooperation. Similarly, Kramer (1981) states that siblings of ill children are placed in a rare situation which requires them to contemplate death, both their sibling's as well as their own. It is through these thoughtful insights that the sibling of an ill child comes to appreciate the importance of making the most of each day.

Although siblings have reported several positive effects resulting from the cancer experience, they still need to cope with all the demands a diagnosis of cancer brings to families, which can produce feelings that are often painful, confusing, and frightening. Evaluating how siblings cope with these uneasy feelings is important when designing interventions to help siblings adjust to the experience of cancer.

Coping with Demands Associated with Pediatric Cancer

How siblings cope with the simultaneous management of new family demands, confusing and frightening emotions, and changes in interpersonal relationships is an important area to investigate in order to help siblings of pediatric cancer successfully adapt to the family illness. According to Lazarus and Folkman (1984) coping is the “process through which the individual manages the demands of the person-environment relationship that are appraised as stressful and the emotions they generate” (p. 19). These authors state that coping is an effort to resolve a situation that is perceived as stressful, and requires the individual to repeatedly appraise the situation which then leads to an action that can be emotional, behavioral, or both.

For example, Walker (1988) interviewed 26 siblings of cancer patients (ages 7-11) and their parents about specific coping strategies that the siblings used to deal with their feelings surrounding the illness. Although parents and siblings differed significantly on their perceptions of coping strategies that the siblings used (i.e., 44% disagreement rate), many of the strategies reported by the siblings included cognitive strategies (e.g., wishful thinking, avoidance, talking to others, reading material about the illness, doing a school project, etc.), or behavioral (e.g., acting out, somatization, attention seeking, playing alone, escaping from family or social contact, etc.). Although most siblings reported using

a combination of cognitive and behavioral strategies, results did not reveal how helpful the siblings felt the strategies were in decreasing their anxiety.

Similarly, Chesler et al. (1991) interviewed 21 siblings (ages 10-21) of pediatric cancer patients about how they coped with all the demands of the illness. Two categories of coping strategies emerged from the interview data. First, many of the siblings used some form of “distraction” when feelings became overwhelming (e.g., try to forget feelings, engage in other activities, etc.). These authors speculated that distraction may reduce the pressure of the immediate situation, however may also increase stress by heightening feelings of isolation. Second, many of the siblings (especially adolescents) “confronted” their uneasy feelings more directly. Strategies included reading about the illness or sharing their feelings with parents. However, even when siblings found conversations with parents successful, the siblings reported that they had mixed feelings about approaching parents with conversations that would cause the parents pain. Other siblings refused to talk to parents due to not wanting to add additional pressure.

Finally, Koch-Hattem (1986) investigated the coping strategies of 33 siblings of pediatric cancer patients (ages 7-18). Results from individual interviews indicated that children and adolescents used strategies such as venting feelings (32%), seeking comfort (23%), and finding other things to distract themselves (50%) in order to cope with their negative feelings surrounding their sibling’s illness. Again, analyses did not reveal how helpful the siblings felt the strategies were in helping them cope with their feelings.

Summary and Conclusions

Siblings are faced with many changes when a brother or sister is diagnosed with cancer. For them, the cancer diagnosis and treatment often brings decreased physical and

emotional attention from parents, increased sibling rivalry that stems from differential treatment of the sick child, frightening and uneasy feelings pertaining to the threat of losing their sibling (as well as their own vulnerability to illness), and increased isolation and tension in their interpersonal relationships. It is also evident from the literature that siblings experience difficulties in adjustment with the same frequency and intensity as the patients themselves (Cairns et al., 1979; Carr-Gregg et al., 1985; Spinetta & Deasy-Spinetta, 1981).

The majority of studies assessing sibling adjustment to the cancer experience have focused on short-term adjustment difficulties. In general, these studies found that 35% to 60% of siblings will display short-term adjustment difficulties (ranging from mild to moderate) after a sibling is diagnosed with cancer. Specific short-term difficulties researchers have noted include feelings of depression, anxiety, anger, guilt, and resentment, as well as attention seeking and acting out behaviors. In addition to behavioral and emotional difficulties, researchers have noted that siblings of cancer patients experience tension in their relationships with peers due to feeling awkward about discussing the illness, which can often lead to increased social isolation (Bendor, 1990; Cairns et al., 1979; Iles, 1979; Haversman & Eiser, 1994; Shapiro & Brack, 1994). Furthermore, when researchers have included family variables in their analyses of sibling problem behavior following the diagnosis of cancer, results have generally indicated significant associations between higher scores on family cohesion, communication, and support, and less reported behavioral problems (Cohen et al., 1994; Dolgin et al., 1997; Haversman & Eiser, 1994; Horwitz & Kazak, 1990; Kramer, 1984; Spinetta & Deasy-Spinetta, 1981) and higher social competence (Cohen et al., 1994, Spinetta & Deasy-

Spinetta, 1981). These associations found in the literature between family variables and sibling adjustment give further justification for the inclusion of familial and contextual variables in studies that assess sibling adjustment to pediatric cancer.

It is important to note that while several short-term behavioral and emotional difficulties have been noted in the literature reviewed on sibling adjustment to pediatric cancer, it does appear that siblings as a group do function relatively well during the course of the illness, with only mild problems for most (LaVigne, 1980). When considering that many of the short-term difficulties experienced by siblings tend to be mild, it is important to understand that difficulties in long-term adjustment will most likely also be very subtle and hard to identify.

Researchers have speculated that siblings of long-term survivors are at an increased risk for residual difficulties in adjustment, especially if the problems resulting from the many emotional demands are not addressed (Cairns et al., 1979; Powazak et al., 1980; Spinetta & Deasy-Spinetta, 1981). However, very little data are available regarding long-term effects of cancer on sibling adjustment, and the studies that are available have methodological shortcomings.

Concerns that have been noted by researchers regarding long-term effects in siblings of cancer patients include feelings of jealousy and resentment over the continued favoritism of the sick child (Kramer, 1984; Peck, 1979), as well as anxiety relating to thoughts about the sibling relapsing or having residual effects from the treatment (Kramer, 1984; Schuler et al., 1985).

It is clear that more research is needed to examine long-term effects in siblings of pediatric cancer patients. However, as stated earlier, given that many of the short-term

effects experienced by siblings are subtle and variable, long-term effects are likely to be hard to detect. This fact argues for the use of instruments that will detect milder adjustment issues (e.g., structured interview protocols) instead of pathology or levels of clinical disturbance, as are assessed in many standardized rating scales of behavior. In addition, given the lack of information about long-term adjustment, a research technique is needed that allows siblings to report their perceptions rather than confirm hypotheses generated in the literature, and allows the researcher versatility in exploring areas where adjustment differences may occur. The use of qualitative methods allows the researcher the flexibility to assess these milder adjustment issues siblings of long-term survivors are likely to experience. For these reasons, therefore, the current study of long-term effects of pediatric cancer employed a qualitative design. However, prior to a description of the study's methods, an introduction to qualitative research methods is provided.

Utilizing and Evaluating a Qualitative Research Design

Introduction to Qualitative Methods

Historically, qualitative research in the United States is rooted in early sociology and anthropology, as researchers in these disciplines attempted to understand how particular people made sense of their worlds (Bogdan & Biklen, 1998). According to these authors, the term “qualitative” is an umbrella term that refers to several research strategies that have certain characteristics in common, including designs that are rich in description, are focused on understanding human behavior from the subjects' own perspective, and are concerned with exploring research questions rather than testing specific hypotheses.

Qualitative research is essentially viewed as a process of inquiry that is based on developing a holistic, complex understanding of a social phenomenon (Campbell, 1997). In addition, the approach is characterized by collecting data in a natural setting where the researcher is the key instrument. The researcher's role in a qualitative design is to thoroughly understand the ways in which people perceive, account for, and manage their lives in order to grasp the specific topic being studied by focusing on depth rather than breadth (Brett & Davies, 1988; Campbell, 1997; Miles & Huberman, 1994). Furthermore, the data in a qualitative study are typically composed of words, rather than numbers, that are generally processed via transcription and coding to generate themes, patterns, and categories to be used in further analyses. Instruments utilized in a qualitative study typically include researcher participation in the setting being studied, observation of the subjects in their natural environment, in-depth interviews (individual or group), and/or an analysis of relevant documents.

Bogdan and Biklen (1998) describe qualitative research designs as having five primary features. First, qualitative designs are "naturalistic" (e.g., data are collected in the subjects' natural environment in order to best understand specific actions that occur in that setting). Second, qualitative designs yield "descriptive data" (e.g., rich descriptions of setting, subjects, context, etc. along with quotations to illustrate presentation of findings). Third, qualitative researchers are "concerned with process," rather than outcomes in data (e.g., focusing on how beliefs are formed and how people come to negotiate meaning in their world). Fourth, the qualitative design utilizes "induction" in theory building (e.g., theory emerges from the bottom up and develops from many pieces of collected information that are related). Lastly, qualitative researchers focus on "meaning" that

evolves from the participants (e.g., utilizing participant perspective while attempting to understand how they make sense of their world).

According to Marshall and Rossman (1999), qualitative designs are useful for exploring a phenomenon for which there is limited understanding, for generating hypotheses that could later be tested in future research, for explaining patterns and identifying relationships that surround a phenomenon, and for describing salient actions, events, beliefs, and attitudes that exist within a certain topic of interest. Other strengths that have been associated with qualitative designs include the fact that the data are typically collected in close proximity to the subjects instead of through mail correspondence, data that are obtained often describe vivid, detailed information that can have a strong impact on and be convincing to the reader, and qualitative data can be useful when one needs to validate or supplement quantitative data (Miles & Huberman, 1994).

Limitations of using a qualitative method include the fact that data collected via interviews or observation can be subject to researcher biases. In addition, this method of data collection and associated coding can be very time-consuming. Lastly, the issue of social desirability exists, in that subjects may not want to be seen in an unfavorable light when being interviewed face-to-face by the researcher (Highlen & Finley, 1996).

These limitations, along with the typical occurrence of a small sample size and researcher characteristics affecting data collection, the qualitative researcher is faced with challenges associated with producing a sound, valid study that can hold up to many of the traditional evaluative standards. For example, they need to plan a research design that is systematic yet flexible, as well as developing a sound conceptual framework that, along

with detailed methodology, will convince readers that the study should be done (Marshall & Rossman, 1999).

Evaluating Qualitative Designs

According to LeCompte and Preissle (1993), “the goal of research is a search for truth” (p. 315). Although the boundaries relating to sample size, selection, and data collection procedures in many qualitative designs tend to be less stringent than in more experimental (i.e., quantitative) methods, qualitative researchers still need to respond to the traditional questions of reliability and validity (e.g., credibility of findings, transferability and replicability of data, ensuring that findings represent participants’ beliefs rather than researcher’s biases, etc.).

Some authors have proposed various constructs to characterize the qualitative paradigm. For example, Lincoln and Guba (1985) suggested that “credibility” (i.e., demonstrating that research was conducted in a way that guaranteed accurate descriptions of subjects, setting, context, etc.), “transferability” (i.e., ensuring that findings can be useful to other situations with similar characteristics), “dependability” (i.e., attempting to justify conditions that may change throughout data collection), and “confirmability” (making sure the findings are due to the data and not to the researcher’s interpretations) are constructs of qualitative research designs that help strengthen findings and, therefore, increase validity.

Another way to strengthen the data collected within a qualitative paradigm is through the use of triangulation. According to Denzin (1989), triangulation involves the use of multiple methods combined in the same study that helps strengthen the validity of data as well as overcome limitations that occur when only one method is employed.

“When a hypothesis can survive the confrontation of a series of complementary methods of testing, it contains a degree of validity unattainable by one tested within the more constricted framework of a single method “ (Webb, 1966, p. 174). There are four types of triangulation including (1) data triangulation, which involves using different data sources, (2) investigator triangulation, which includes utilizing multiple observers in data collection, (3) theory triangulation, which involves the use of various viewpoints in confirming data, and (4) methodological triangulation, which includes “within-method” (i.e., applying multiple strategies within one method of data collection), and “between-method” (i.e., utilizing multiple methods in the same study to collect data). According to Mitchell (1986), when two or more different examples of a particular type of triangulation are present within a study, that study is said to be triangulated.

The goal of triangulation in any study is to increase the confidence in the trustworthiness of the data and its interpretation (Breitmayer, Ayers, & Knafl, 1993). In the majority of social science research using triangulation, when two or more methods are used in the same study, the purpose of triangulation is to “confirm” hypotheses that are generated by the data (Breitmayer et al., 1993). In recent years, however, investigators have identified additional purposes served by using triangulation in qualitative designs. For example, Fielding and Fielding (1986) linked the term triangulation to the goal of “completeness.” Specifically, by using two or more different data sources, investigators can reveal the varied dimensions of the topic, whereby each data source contributes another piece to the puzzle.

Along with using multiple sources of information in data collection, Marshall and Rossman (1999) list four criteria researchers should use when conducting a qualitative

study. First, these authors state that the study's design and methodology need to be explicitly detailed. Specifically, researchers are obligated to describe all data collection techniques, recording procedures, steps in analysis, and all ethical issues in order for readers to judge the study's soundness. Additionally, researchers need to express all biases and assumptions that could have affected findings and interpretations. Finally, alternative explanations need to be explored and negative instances investigated.

The second criterion that was stated by Marshall and Rossman (1999) is that the researcher needs to describe the relevance of the research questions. Specifically, the researcher needs to discuss the relationship between the current study and previous studies that exist in the area of interest, as well as translate data into interpretations that are accurate and can be easily understood.

The third criterion involves acknowledging the study's limitations while also drawing attention to the study's potential for transferability. Qualitative researchers are not as concerned with whether or not the findings can be generalized, but to which settings and which subjects they can be transferable.

The fourth criterion that is listed by these authors relates to the organization and management of data. Researchers need to describe how raw data will be preserved and what will happen to data once study is complete.

In summary, qualitative methodology is naturalistic, interpretive, subjective, and grounded in the perspectives of the participants involved in the study. The descriptive and exploratory nature of qualitative designs is useful when targeting an area for which our understanding is limited. By providing rich descriptions of complex situations, researchers can understand more completely the beliefs, actions, and behavior of the

participants involved, as well as comprehend the processes by which individuals develop meaning in their lives.

Given that an important aspect of the current study involves sibling perceptions of the cancer experience and asks questions pertaining to how living with a sibling affects one's adjustment, using richly detailed case studies, in which the siblings speak for themselves, is an appropriate research method. The current study included method triangulation (i.e., individual and group interviews with siblings) to help "confirm" results, and data triangulation (i.e., sibling and parent informants) to help "complete" the understanding of sibling adjustment to cancer. Using multiple methods as well as multiple informants helped to increase the validity of the findings, as well as our confidence that the findings are robust rather than an artifact of the data collection techniques, or the particular sample of children selected.

CHAPTER III: STATEMENT OF THE PROBLEM AND RESEARCH QUESTIONS

Statement of the Problem

The previous sections have provided a review of the literature concerning sibling adjustment to pediatric cancer. Due to advanced and more effective treatment combinations, pediatric cancer has gone from an illness once considered to be inevitably fatal to one that is likely to be survived. However, treatment protocols place large emotional, financial, and time demands on the family. In addition, the outcome of cancer treatment is still uncertain, and families not only face the stress of a experiencing a member's illness and painful treatment, but also the stress of knowing the child may not survive the illness and treatment.

Sibling effects of pediatric cancer became a topic of research interest when researchers who had used siblings as "controls" to assess the effect of cancer found that the siblings fared as poorly, or worse, than the pediatric cancer patient (Cairns et al., 1979; Carr-Gregg et al., 1985; Spinetta & Deasy-Spinetta, 1981). Since that time, a number of researchers have investigated the social, behavioral, and affective outcomes for siblings with cancer (Barbarin et al., 1995; Bender, 1990; Carpenter & Sahler, 1991; Chesler et al., 1991; Evans et al., 1992; Havermans & Eiser, 1994; Iles, 1979; Kramer, 1984; Koch, 1985; Koch-Hattem, 1986; Lavigne & Ryan, 1979; Martinson et al., 1990; Sahler & Carpenter, 1987; Sargent et al., 1995; Shapiro & While, 1996; Spinetta, 1981; Walker, 1988). This research has generally focused on documenting decrements in siblings' functioning (e.g., attention seeking, acting out, tension in interpersonal relationships, etc.) when a brother or sister undergoes cancer treatment.

Overall, these studies have lacked a theoretical framework for understanding how pediatric cancer might exert an impact on siblings' adjustment. In part, this shortcoming in the literature is due to the lack of well specified general theories of family functioning and its impact on typical child development.

The wide-ranging effects of pediatric cancer on families make it likely that siblings' development may be affected through multiple pathways, both direct and indirect. For example, adolescents' feelings of invulnerability to illness or death may be directly changed by having witnessed a sibling's life-threatening illness. Indirect effects may occur when parental functions (e.g., monitoring) are disrupted by parent absence or lack of time or energy due to treatment demands for the sick sibling.

In describing the multiple pathways by which cancer may affect siblings, Patterson and colleagues' model of the role of parenting and contextual factors in the development of antisocial behavior was used as the basis of a discussion of how cancer affects siblings' adjustment in many ways. This model was selected because of its specificity in linking child adjustment with parenting and family systems constructs. When applying Patterson's model to families coping with pediatric cancer, it becomes clear how aspects of family functioning (i.e., parental monitoring, availability, involvement, discipline, coping, and family cohesion and communication) can mediate the effect of cancer on individual sibling adjustment.

Despite the lack of a theoretical framework for understanding pediatric cancer's impact on siblings, numerous studies have examined this topic and these studies have been reviewed in the preceding chapter. However, the findings from this literature must be interpreted cautiously due to variations in methodology across studies that are likely to

have affected their findings. Among the methodological issues that affect our ability to draw conclusions across cancer sibling studies are: (a) amount of time since the illness when effects are assessed (short- vs. long-term effects), (b) assessment approach (quantitative approach or qualitative), (c) informant (parent vs. self-report), (d) status of cancer patient (survivor or deceased), (e) age at which the sibling is assessed, and his or her age at the time of the illness, and (f) instrument focus and format (e.g., pathology or adaptive functioning/structured vs. open-ended).

The variations across studies on the dimensions listed above make it difficult to draw conclusions across studies. Methodological issues and other potential confounds in study designs also make interpretations of this literature difficult. For example, several studies have not distinguished between long- and short-term effects (e.g., Barbarin et al., 1995; Dolgin et al., 1997; Sahler et al., 1994; Sargent et al., 1995), used a wide age range of subjects (e.g., Chesler et al., 1991; Evans et al., 1992; Gogan et al., 1977; Koch, 1985; Kramer, 1984), used inappropriate informants such as parents for internalizing (e.g., Barbarin et al., 1995; Cohen et al., 1994; Horwitz & Kazak, 1990; Peck, 1979), or used only a small number of subjects (e.g., Bendor, 1990; Haversman & Eiser, 1994; Iles, 1979; Shapiro & Brack, 1994).

Despite these shortcomings, some general conclusions about the impact of pediatric cancer on siblings can be drawn, particularly when one examines the short-term effects on siblings. In general, a significant percentage of siblings of pediatric cancer patients have been found to experience feelings of sadness, jealousy, anger, anxiety, guilt, and resentment, that can lead to internalizing and externalizing problems, along with tension in their interpersonal relationships. In addition, a number of family variables (i.e.,

high cohesion, communication, and support) are associated with fewer emotional and behavioral difficulties.

Conclusions about the long-term effects of pediatric cancer on siblings must be much more tentative. There is very little information available about long-term effects cancer has on siblings, even though it has been suggested that siblings of long-term survivors may have residual difficulties (Cairns et al., 1979; Powazek et al., 1980; Spinetta, 1981). Problems in assessing long-term effects include low subject accessibility; lack of available instruments that are sensitive enough to detect milder problems or changes that are not problematic; and difficulty in determining how the intervening years have affected children's recall and interpretation of their experiences during their siblings' cancer treatment and recovery.

The purpose of the present study was to examine siblings' and parents' perceptions of the pediatric cancer experience and its impact on the siblings' subsequent long-term adjustment. As noted above, there are few studies of long-term adjustment and these have had serious methodological problems. The methodology of the present study addressed several of these concerns. Specifically, the study limited the subject population to one age group, adolescents; required that the cancer diagnosis have occurred within a specified time frame (i.e., at least three years prior to investigation); attempted to use only families in which the cancer patient has survived; and used multiple informants and triangulation to strengthen the generalizability of the results.

A qualitative research design was selected because of the lack of studies on this topic. The use of a methodology and design that permitted siblings and parents to speak for themselves in their own words and provided rich, in-depth information was appropriate

for identifying areas for future follow-up studies with larger samples and more structured instruments. The design was useful for generating hypotheses about the long-term effects of being the sibling of a pediatric cancer patient, and in understanding the views of siblings and parents about the cancer experience.

The design also has limitations. Generalizability is limited due to the small number of subjects and the restricted age range. In addition, the retrospective reports of siblings of pediatric cancer patients (and their parents) about the effect of cancer on siblings' adjustment, as well as helpful (and unhelpful) support strategies must be interpreted carefully due to the reconstructive aspects of memory and the reinterpretation of events over time. However, these reports are helpful in understanding what events are still salient for siblings years later. Furthermore, an understanding of siblings' long-term perceptions and interpretations may be helpful in thinking about ways that families can be helped through the early cancer experience, and how long-term sibling adaptation and healthy coping can be promoted.

Research Questions

1. Years after diagnosis and treatment, what amount and types of illness-related information do healthy siblings perceive as being most helpful in understanding and coping with their siblings' cancer? What role did involvement in the patient's treatment play?
2. When healthy siblings of post-treatment pediatric cancer patients look back to the time of their sibling's diagnosis, what do they report as being their most significant concerns?

3. When healthy siblings of post-treatment pediatric cancer patients look back on their sibling's illness, what aspects of the whole cancer experience do they perceive as being the most salient?
4. What issues or concerns continue to be prominent to siblings of pediatric cancer patients years after their sibling's diagnosis and treatment?
5. According to siblings of post-treatment, pediatric cancer patients, what coping strategies and interventions are perceived to have been the most helpful during the early phases of the treatment, as well as throughout their sibling's illness?
6. What do siblings report are the positive changes that resulted from their cancer experience?

CHAPTER IV: METHOD

Participants

Eleven siblings of pediatric cancer patients and their parents participated in the study. Demographic characteristics for the sample are presented in Table 2. Ten of the participants (91%) lived in two parent homes when their sibling was diagnosed. Seven (64%) remained in two-parent homes at the time of the investigation. The modal number of children in each home was 3 with a range of 2 to 10 children. Parents' represented a variety of occupations including professionals/administrators, educators, secretary, laborer, and homemaker. Although information on religious affiliation was not collected as part of the demographic information, it is important to note that 40% of the families in the study identified themselves as Mormons.

Table 3 presents information on the participants' siblings and their diagnoses. Four of the participants had a sibling diagnosed with a brain tumor (i.e., medulloblastoma), four had a sibling diagnosed with a solid tumor (e.g., osteosarcoma), and three had a sibling diagnosed with leukemia (i.e., acute lymphoblastic leukemia). All of the participants' siblings received a combination of chemotherapy agents as part of their treatment protocol, and the majority also received radiation (64%) and/or surgery (73%). One of the participants' siblings received a bone marrow transplant due to the nature of the malignancy. The siblings of the participants received between 10 and 36 months of treatment, and were 3 to 9 years post diagnosis at the time of the investigation. All of the participants' siblings were in remission at the time of the investigation, except one, who had died four years prior to the investigation.

Table 2

Demographic Characteristics of Participants

<i>Characteristic</i>	<i>N</i>	<i>%</i>			
Gender					
Male	4	36%			
Female	7	64%			
Ethnicity					
Caucasian	8	73%			
Hispanic	3	27%			
Siblings' Relationship to Patient					
Older Siblings	7	64%			
Younger Siblings	4	36%			
			<i>M</i>	<i>SD</i>	<i>Range</i>
Age at Time of Investigation			17.1	(1.37)	15.2 - 18.9
Age at Time of Sibling Diagnosis			10.5	(2.3)	8.0 - 15.0

Table 3

Diagnosis and Treatment of the Participants' Siblings (i.e., Patients)

<i>Characteristic</i>	<i>N</i>	<i>%</i>			
Diagnosis					
Leukemia	3	27%			
Brain Tumor	4	36%			
Solid Tumor	4	36%			
Treatment					
Chemotherapy	11	100%			
Radiation	7	64%			
Surgery	8	73%			
Bone Marrow Transplant	1	9%			
			<i>M</i>	<i>SD</i>	<i>Range</i>
Length of Treatment (months)			20.8	(9.4)	10.0 – 36.0
Time Since Diagnosis (years)			6.45	(2.3)	3.0 – 9.0

Instruments

Table 4 presents the instruments used in the current investigation, and illustrates how specific questions on each instrument were linked to the research questions posed in the study. The instruments used for analysis included an individual sibling interview, a group sibling interview, and an individual parent interview. In addition, a “time-line” exercise was used to establish rapport with the participants. Each instrument is described below. Because several of the instruments were developed or adapted specifically for this study, the description also includes a rationale and research base for the items on it. See Appendices A through D for specific interview protocols.

Time-Line Exercise

Description. This instrument (Appendix A) was adapted from Korb-Khalsa, Azok, and Leutenberg’s (1989) time-line exercise titled “*My Life: Past, Present, Future.*” It was designed to help siblings of pediatric cancer patients remember significant events relating to their brother or sister’s illness by plotting times, events, and feelings associated with the cancer experience. With the instrument, a time line is presented on a piece of paper to the participant. The participant then marks points on the time line that signify important events in his/her life from the earliest memory to his/her current age. The line is drawn down the middle of the page (horizontally) to allow the subject to denote whether the event is a positive (i.e., above the line) or negative (i.e., below the line) experience.

Rationale. The purpose of this exercise in the current study was to establish rapport with each participant before the individual interview was administered. The exercise also was designed to help the participant remember back to when his/her sibling

Table 4

Instruments Used in Investigation and Links to Research Questions

<i>Research Question</i>	<i>Instrument</i>	<i>Questions</i>
1. Information about diagnosis/ treatment	Individ. Interview	1
	Group Interview	1 (a,b)
	Parent Interview	1
2. Initial concerns	Individ. Interview	2 (a)
	Group Interview	2 (a)
	Parent Interview	2 (a)
3. Most salient aspects of cancer experience	Individ. Interview	3, 4
	Group Interview	3, 4
	Parent Interview	3, 4
4. Current issues of concern	Individ. Interview	5 (a, b)
	Group Interview	5, 2 (c)
	Parent Interview	5
5. Coping strategies	Individ. Interview	2 (b, c); 5 (c); 6(a, b)
	Group Interview	2 (b); 6 (d, e)
	Parent Interview	2 (b, c); 6 (a, b)
6. Positive changes	Individ. Interview	6 (c)
	Group Interview	6 (c)
	Parent Interview	6 (d)

was diagnosed, and to be able to attach dates, people, and most importantly, feelings to the specific events surrounding the illness. The researcher can then refer back to the timeline in the individual interview in order to collect more specific information about the events the sibling felt were important in his/her life.

Individual Interview Protocol

Overview. The individual interview protocol (Appendix B) assessed siblings' perceptions of the cancer experience, and how living with a brother or sister who has undergone treatment for cancer has affected them. Developed by the investigator after a thorough literature review on effects of pediatric cancer on siblings, the interview is divided into six blocks of questions that address the following categories of information: siblings' (a) feelings on how illness-related information was communicated at the time of diagnosis, (b) initial concerns at the time of diagnosis and coping strategies utilized at this time, (c) perceptions of family changes during the initial phases of treatment, (d) insights into changes in other areas of the sibling's life during treatment, (e) views on the sibling's current functioning post-treatment, and (f) thoughts relating to areas that could be helpful in planning future interventions for siblings of pediatric cancer patients.

Description. Individual items were drawn from other studies that have used such questions to ascertain effects of the cancer experience on siblings' psychosocial functioning (Koch, 1985; Koch-Hattem, 1986; Lauer, Mulhern, Bohne, & Camitta, 1985; Martinson et al., 1990; Menke, 1987; Walker, 1988). The first block of questions dealt with sibling knowledge about their brother or sister's cancer, as well as the quality of communication that occurred at the time of diagnosis. A general question about

becoming aware of the diagnosis was included to ascertain whether or not communication, or lack thereof, was/is an issue to the siblings. Prompts that followed included questions pertaining to where information about the initial diagnosis came from, whether the information was sufficient, and what other information would have been helpful to know at that time. These items were included because it has been reported in the literature that siblings are often given limited information about the specific aspects of their sibling's cancer and associated treatment effects and may develop their own perceptions of the illness (Carpenter & Levant, 1994).

The second block of questions dealt with sibling concerns at the time of diagnosis and during the initial phases of treatment. Several investigators have documented anxiety responses in siblings of pediatric cancer patients (Balk, 1983b; Bendor, 1990; Cairns et al., 1979; Evans et al., 1992; Kramer, 1984; Martinson et al., 1990; Sahler & Carpenter, 1989; Walker, 1988). Individual items on the questionnaire addressed specific affective topics such as worrying about their sibling's health, fearing that they would also become ill, and worrying about what changes would occur in their family (e.g., financial, logistical, etc.) as a result of the illness. Questions related to coping at or near the time of diagnosis were also included to identify adaptive and maladaptive coping responses.

Koch-Hattem (1986) identified various adaptive coping strategies that siblings utilized in dealing with negative feelings associated with the cancer experience. Therefore, it was useful to ascertain whether the siblings in the current study utilized similar coping techniques as well.

Changes in family relationships have been discussed at length in the sibling oncology and bereavement literature. Specific aspects of family functioning (e.g.,

cohesion, expressiveness, role/responsibility changes.) have been reported as being significant factors that can affect adjustment to the family cancer experience (Brett & Davies, 1988; Iles, 1979; Kazak & Meadows, 1989; Sahler & Carpenter, 1987; Sawyer et al., 1986). Therefore, the next block of questions dealt with family functioning, and included questions about changes in the relationships between the sibling and family members, alterations in roles and responsibilities, and general changes in the family unit. Again, the initial question in this block was very general and was designed to elicit important issues relating to the family unit as viewed by the siblings. Prompts that were included focused on specific alterations in family responsibilities, as well as feelings associated with these changes.

Within this block were also questions that dealt with changes in other areas of the sibling's life during the time their brother or sister was receiving treatment for cancer. Prompts focused on the sibling's interpersonal relationships, school functioning (e.g., grades, ability to concentrate), and affective disturbance (e.g., sleep and appetite patterns, general mood). Research suggests that living with a child with cancer can have effects on siblings' social relationships, especially in terms of changes in the way peers (and others) treat them after diagnosis and throughout their sibling's treatment (Brett & Davies, 1988; Hogan, 1988; Hogan & Balk, 1990; Walker, 1988). Changes in academic functioning have also been reported in the literature (Balk, 1983a; Davies, 1993; Sourkes, 1981; Spinetta, 1981), and were thus addressed in the protocol. Finally, there have been several studies that have documented affective changes in siblings of pediatric cancer patients (Balk, 1983; Bendor, 1990; Carpenter & Sahler, 1991; Evans et al., 1992; Kramer, 1984; Martinson et al., 1990; Spinetta et al., 1981). For example, Sahler and colleagues (1994)

found that siblings of pediatric cancer patients were two to four times more likely to reach criteria for clinical disturbance (including acting out behavior) than were siblings of healthy children.

The next block of questions dealt with siblings' perceptions of how they were currently functioning, given that their sibling with cancer had completed treatment and were in remission. Prompts consisted of questions that addressed specific areas of the sibling's life that have changed since experiencing cancer in the family, such as the relationship between the sibling and their parents (as well as with their sick sibling), differences in the family unit, and specific changes they have identified in themselves.

The next block of questions followed-up on specific concerns and worries that were addressed earlier in the interview. Specific questions assessed if their initial concerns still existed, as well as what coping strategies were used when the sibling has these concerns.

The last block of questions related to more general aspects of the cancer experience with the purpose of gaining insight into how the siblings perceived the experience as a whole, years after initial diagnosis. For example, the interview protocol asked about any positive changes that siblings' believe resulted from the cancer experience. Research does support the finding that siblings often note aspects of the cancer experience that led to positive changes in areas such as their relationships with family members, opportunities to learn responsibility, or increased maturity (Davies, 1995; Evans et al., 1992, Kramer, 1981).

These last questions also addressed specific areas that could be useful in planning interventions for future siblings of pediatric cancer patients. Specifically, the siblings were asked to identify the most helpful person during the diagnosis and treatment, the

most difficult aspect of having a brother or sister with cancer, and what would have helped them during the whole cancer experience.

Group Interview Protocol

Overview. A focus group interview protocol was developed to be used with all of the siblings previously interviewed individually. The group interview protocol was structured in the same way as the individual interview protocol so that siblings were able to discuss the issues in a group the same issues that they discussed individually (Appendix C). Like the individual interview protocol, the group interview protocol was divided into six blocks of questions including (a) the siblings' thoughts on how illness-related information was communicated at the time of diagnosis, (b) initial concerns at the time of diagnosis and coping strategies used at this time, (c) changes occurring in the family during the initial phases of treatment, (d) other changes that occurred in the siblings lives during this time, (e) the siblings' current functioning, and (f) areas for intervention and general thoughts regarding the cancer experience as a whole.

Rationale. According to Stewart and Shamdasani (1990), focus groups "are useful for exploring the way particular groups of individuals think and talk about a phenomenon, for generating ideas, and for diagnostic information. For these purposes, focus groups represent a rigorous scientific method of inquiry" (p.140.)

For the current investigation, the focus group was chosen for several reasons. First, using a focus group allowed the researcher an opportunity to provide feedback to the participants in terms of what other siblings felt was important to them when describing the cancer experience. Studies have documented the efficacy of group discussions with siblings of pediatric cancer patients (Adams-Greenly, 1984; Bendor, 1990; Cunningham et

al., 1981). For example, Adams-Greenly (1984) found that the siblings of pediatric cancer patients in her study valued the opportunity to discuss issues of importance and realized they were not alone in their feelings.

Another reason for using a focus group for data collection is the fact that some valuable information may only become apparent in a group setting. For example, Stewart and Shamdasani (1990) point out advantages for using a focus group instead of, or in addition to, an individual interview. These advantages include the fact that “snowballing” (i.e., a comment by one subject will trigger a comment by another subject) can occur in a group setting, and thus produce the widest range of ideas and information. Additionally, some members of the group may feel more “secure” sharing feelings in a group setting due to the fact that the focus is more on the group as a whole, and less on each individual. These authors also state that answers in a focus group are typically more spontaneous than in an individual interview because group members tend to volunteer responses, instead of responding only when being asked direct questions. The authors believe that this spontaneous interaction produces insights that are difficult to obtain solely from an individual interview.

The last reason for using a focus group in the present study was to help strengthen the data obtained through the time-line exercise, individual interview, and the parent interview. The use of multiple methods and informants allowed the researcher to assess for consistency of findings, which is one means to strengthen the study’s reliability and validity.

Description. As the questions for the focus group depended on responses from the time-line and individual interviews, only an outline of topics addressed is presented in

Appendix C. The first block of questions focused on the siblings' responses to the knowledge and communication questions in the interview. The siblings were given feedback about what some of the group members felt about these issues, and then asked if others had similar experiences. The same type of questioning occurred for the other topics addressed such as initial concerns, coping with worries, changes in family functioning and other aspects in the sibling's life, current functioning, and suggestions for intervention for siblings who will go through these experiences in the future.

Siblings were encouraged to provide as much information as they felt relevant, but also to stay on the topic being addressed. The researcher's role was to ask and clarify questions, elicit active participation, encourage the subjects to respond to each other's ideas, and redirect the discussion as necessary in order to ensure that research questions were being addressed. In addition, it was also important to allow the participants the opportunity to discuss what is important to them.

Parent Interview Protocol

Overview. An interview protocol for parents was developed to assess their perception of the sibling's thoughts and beliefs relating to the cancer experience (Appendix D). The items on the parent interview protocol mirrored the items on both the individual interview protocol, as well as on the group interview protocol, in order to strengthen the data obtained from the siblings individually and in the focus group. Therefore, the protocol addressed areas such as (a) knowledge and communication, (b) initial concerns and coping strategies, (c) changes in family functioning, (d) changes in other aspects of the sibling's life, (e) current functioning, and (f) areas for intervention.

Rationale. Many studies have used parent data along with sibling data to strengthen findings (Demi & Gilbert, 1987; Hogan & Balk, 1990; Horwitz & Kazak, 1990; Martinson, 1990; Sahler et al.; Sahler & Carpenter, 1988). Although there have been differences reported between parent and sibling informants (Walker, 1988), it has been documented that parents are a valuable source of information to be used in conjunction with other informants, such as siblings themselves.

Description. The first block of questions dealt with parents' recall of how the sibling initially became aware of the diagnosis, and who was involved in communicating the information to the sibling. Parents were prompted with questions relating to their feelings on whether enough information was given to the siblings at the time of diagnosis, as well as what, if any, additional information they would have conveyed at this time.

The next block of questions dealt with the parent's perceptions of what initial concerns the sibling had at the time of diagnosis and what coping strategies were used to deal with the concerns. Prompts included asking parents if the sibling worried about illness-related aspects of the patient's health or their own well-being, as well as asking if the sibling worried about issues such as financial hardship on the family or logistical concerns. Parents were then asked if they believed the sibling still had concerns regarding the areas they mentioned.

The next block of questions dealt with specific changes that occurred in the family at the time of diagnosis and throughout the initial phases of treatment. Prompts in this category included asking the parents if they thought there were changes in specific family roles and responsibilities, and how they felt the sibling dealt with these changes in the family.

Parents were also asked to describe other changes that took place in the sibling's life during the initial phases of treatment. Prompts for this question related to asking parents about any changes in the sibling's relationships with his/her peers, academic functioning, and overall mood.

The next block of questions focused on the parent's perception of the sibling's current functioning now that treatment has ended and the child was in remission. Parents were prompted to address their thoughts on the sibling's relationship with them, with the child who received treatment, and with the family in general.

The last block of questions focused on information that could be useful in planning interventions for siblings of pediatric cancer patients. Specific questions related to the parent's perception of who they felt was the most helpful to the sibling during the child's illness, what they felt would have been helpful to the sibling at the time of diagnosis and throughout the course of treatment, what they think was the most difficult aspect of the illness that the sibling had to deal with, and what positive effects resulted in their family as a result of their child undergoing treatment for cancer.

Procedure

Setting

Participants in the current study were enrolled for one week at Camp Ronald McDonald for Good Times (CRMFGT) summer camp. CRMFGT is a non-profit organization that offers the largest year-round recreational camping program for children with cancer and their families in the United States (CRMFGT, 1997). The camp is free of charge to families, with the entire cost of camp being covered by year-long fundraising, as well as donations offered from corporate donors, individuals, and other foundations.

Along with sessions for patients ages 7 to 18, families with younger patients, and Spanish-speaking families, the camp offers two, week-long sessions in the summer that are devoted solely to the siblings (ages 7 to 18) of pediatric cancer patients.

Siblings who attend one of the two summer sessions of the camp live in cabins, according to age, that are typically composed of 8 to 12 campers and 2 to 3 cabin counselors. Activities are scheduled on a daily basis and include sporting events, arts and crafts, archery, swimming, horseback riding, newspaper writing, drama, computers, and a high-rope "Courage Course" that is supervised by trained recreational personnel. Evenings at camp are generally spent at campfires, where campers sing or perform dramatic skits or in whole-cabin activities, which are designed for cabin bonding and planned by each individual cabin. There is also a dance that occurs towards the end of the week for the entire camp. In addition, campers are given ample time for letter-writing, socializing with other cabins, and resting.

Recruitment

Approval for this study was requested and granted by the executive committee at Camp Ronald McDonald for Good Times (CRMFGT), and was also granted by the Institutional Review Board of the North Carolina State University. After approval was granted by CRMFGT, a list of siblings attending one of the two-week summer sessions was reviewed by the Director of Camping to determine which siblings met criteria for selection in the study. Criteria for inclusion into the study included that the sibling: (a) was between the ages of 15 and 18 at the time of investigation; (b) was at least eight years old at the time of his/her sibling's diagnosis; (c) did not have any significant health concerns; (d) lived with the patient during the treatment phase; and (e) identified English

as his/her primary language. Additionally, all participants needed to be the sibling of a pediatric oncology patient who (a) was diagnosed at least three years prior to the investigation; (b) received chemotherapy as part of the treatment protocol; and (c) was currently alive and in remission.

After the Director of Camping reviewed the list and eliminated siblings who did not meet all study inclusion criteria, the list was sent to the primary investigator to begin subject recruitment. All of the parents of the siblings who had been identified by the Director as meeting the criteria for the study received a letter in the mail (Appendix E) explaining the purpose of the study, what was involved in participating, and an assurance that declining to participate in the study would not have any negative effect on their relationship with Camp Ronald McDonald for Good Times. Phone calls followed the mailed letters to insure that the information was received and to ascertain willingness to participate. Three telephone attempts were made before eliminating the subject from the sample. Out of the 27 potential participants on the revised list, five declined to participate, four failed to meet one or more of the study criteria (e.g., did not live with the sibling during treatment, the sibling was not in remission), and eight could not be contacted via phone. Ten siblings and their parents agreed to participate in the current investigation.

Of these, one family did not meet the inclusion criteria because the sibling with cancer had died. However, because the family was mistakenly sent the recruitment letter, and indicated a strong interest in participating in the study, they were included. One other family requested that a second sibling at the camp be included in the study and this request

was also granted. With the inclusion of these siblings, eleven siblings served as study participants.

Consent

On the first day of camp, the researcher introduced herself to participants and their parents. The researcher explained that she had been involved in the camp for eight years, serving as both a cabin counselor and unit director. The researcher also explained that her role for this particular week was only that of a researcher, and that she would be conducting both the individual and the group interview. After answering questions, written consent to participate in the investigation was obtained for each participant and parent (Appendix F). In addition, a background questionnaire was completed by each parent (Appendix G).

Time-line Exercise and Individual Interview

The time-line exercise and individual interview were conducted with each participant near the beginning of the week at camp in a quiet area, and took between 45 and 60 minutes to complete. At the beginning of this first session, participants were again assured of their anonymity of their responses. Participants were told that the information provided would be held in confidence unless the information revealed indicated potential harm to either themselves or someone else. If such information were to be disclosed, regular camp policies regarding notification of appropriate personnel would apply. All participants were given the opportunity to express interest in seeking additional help relating to the topics discussed in the interview. No additional help was requested by any of the participants. The researcher also reminded each participant that their interview was to be audiotaped to allow the researcher to conduct analyses after the interviews were

complete. The researcher then proceeded with the time-line exercise and individual interview protocol.

Group Interview

Preliminary analysis. Preliminary data analysis occurred after all the individual interviews with the siblings were completed, but before the focus group took place. The purpose of the preliminary analysis was to allow the researcher an opportunity to review interview responses in order to compile a list of common themes that would be discussed in the focus group. No transcription of interviews occurred at this stage of data analysis. Instead, the researcher reviewed the written notes from each interview and began generating categories that appeared to characterize the siblings' responses. These categories were "common sense" categories, or categories which might have been generated by any knowledgeable observer reading the responses and noting similarities. The coding scheme was expected to shift as the researcher progressed through the interview protocols, and began to note more subtle patterns that may not have been apparent in the first or second interview. When this occurred, the researcher refined the categories and recoded all responses in earlier interviews. This process is called "constant comparison" (Strauss & Corbin, 1994). When all of the interview material was classified according to these categories, the researcher then used these categories to provide examples to the participants for each main topic area in the group interview. For example, when the researcher asked the group about the information provided to them at the time of diagnosis, she then provided them with examples of responses (e.g., "Some of you said you did receive enough information, while others of you felt the information received was not sufficient, and these were some reasons...").

Interview. The group interview occurred after all of the individual interviews were completed, and lasted approximately 90 minutes. The group began with introductions of the researcher as well as the group members. The siblings were again reminded that the group session would be audiotaped, and that their willingness to terminate at any time was still an option. The researcher then thanked the participants for their time in the individual interview as well as the group interview, reminded them of the purpose of the study, and established ground rules for the group. Although a list of rules was developed *a priori* by the researcher around confidentiality and respect for others, the researcher also asked the participants to develop their own rules for the group. During this process, any rules that were not addressed by the members were added by the researcher.

Parent Interviews

Parent interviews occurred from one to three weeks following the camp session via telephone. Parents were given the choice of which parent would be interviewed based on who they thought could contribute the most information about the sibling's functioning during the treatment phase. All families chose the mother of the sibling to be interviewed. The interviews lasted approximately 45 minutes. The parents were reminded that the interview would be audiotaped. They were also reminded that their anonymity would be preserved and their confidentiality protected.

CHAPTER IV: RESULTS

Description of Data Analysis Strategy

Prior to formal data analysis, all interviews (i.e., individual, group, and parent) were transcribed to ensure completeness and accuracy during the subsequent qualitative coding. The researcher then transferred the transcribed data into a software program that is specifically designed to facilitate analysis of qualitative data (i.e., The Ethnograph). The researcher employed a constant comparative method of analysis (Miles & Huberman, 1994), a method of data analysis that entails a search for patterns or themes within the data. The first step in the qualitative data analysis was an initial review of the interview transcripts and creation of content codes derived from the responses provided by participants to the research questions posed. For example, the response “I wanted to know more about the specific type of cancer my sister had” to Research Question 1 concerning information that would have been helpful would be assigned the code, “Details about cancer diagnosis.” As content codes were created, they were then assigned to quotes from each transcript. As new codes emerged during the content analysis procedure, the researcher then went back through the data and recoded the already reviewed data files (i.e., constant comparison). This procedure ended once all data files were coded and no new codes emerged. The researcher then met with a trained ethnographer to refine all the established codes, which included generating a list of “rules” for the coding process. The researcher then went through all the data files using the refined codes and code rules, and finalized the coding process.

To determine the reliability of the codes generated, a reliability check was performed. Specifically, the researcher trained a doctoral level psychology research fellow

to use the already established codes and rules, and apply them to a sample of the data set (20% of all data files). The reliability of the coding was assessed by calculating the percentage agreement between the two raters. Agreement between the two raters was 89%, with disagreements between coders resolved through discussion.

The researcher then ran "searches" on the codes within each data source (i.e., individual interview, parent interview, group interview) to begin generating themes. The display of all data from one code provided an organized method to examine findings, reconsider coding categories, and draw conclusions.

The data obtained from the individual interviews, the focus group, and the parent interviews were then compared in order to determine which themes were consistent across measures and informants. Triangulation occurred on two levels. Methodological triangulation was used to help "confirm" findings, in that the researcher used two different, but complementary methods in the study (i.e., sibling individual interviews and sibling focus group) to establish convergent validity. In addition, data triangulation was used to "complete" the understanding of sibling adjustment to cancer by the use of two different informants (i.e., siblings and parents) (Breitmayer et al., 1993). These types of triangulation allowed for conclusions to be verified, or indicated that alternative explanations needed to be explored. Triangulating the data lessened the risk for overinterpretation of data that is obtained from a single data collection technique, and served as a validation check. More confidence and interpretation occurred for themes that were observed across multiple subjects, multiple data collection techniques and across informants.

Results

In this section, the results for each individual research question are presented in a summary table, broken down across the three data sources (individual sibling interviews, sibling focus groups, and individual parent interviews). The major themes are described for each data source, including comparisons between data sources. In the group interview, responses could not be attached to particular participants. Therefore, percentages of respondents could not be calculated. Therefore, findings were reported as “salient” if the majority of participants endorsed the finding, and “present” if some (or half) of the participants endorsed the finding. Occurrences of discrepant cases are also reported when relevant. In cases where a data source did not target a particular aspect of a research question, the section was omitted.

Research Question One

Years after treatment, what amount and types of illness-related information do healthy siblings perceive as being most helpful in understanding and coping with their siblings’ cancer? What role did involvement in their sibling treatment play?

Table 5 displays the responses of siblings (individual and group interviews) and parents to these questions.

Amount of Illness-Related Information

Based on nine out of 11 sibling interview responses (two failed to respond to the query), most siblings said they were not given enough information (66%). The remaining 33% stated that, under the circumstances, they received sufficient information. When asked why they felt information was not presented to them, many said that their parents

Table 5

*Percentages of Responses to Details of Information Provided**at Time of Diagnosis*

<i>Category</i>	<i>Percentage</i>		<i>Response</i>
	<i>Sibling</i>	<i>Parent</i>	<i>Group</i>
Received insufficient information by parents	66	40	P
Other information that would have been helpful			
- Details about cancer diagnosis	64		
- Treatment details/side effects	36		P
- Family changes that were about to take place	18		
- Reassurance that the cancer was treatable		10	
Sibling involved in patient care			
- Actively involved	50	56	
- Uninvolved	30	10	
- Moderately involved	20	33	
Involvement in patient's care was important	80	90	S

S = "Salient" - majority of group endorsed

P = "Present" - some (or half) of group endorsed

NP = "Not Present" - question was asked and group did NOT endorse

Blank = question not asked directly and/or was not addressed by group

thought they were too young to understand (55%), and/or were concerned that more information would upset them (45%).

“Nothing was really told to me because I knew my parents thought I wouldn’t understand it. They just said that he had a bad disease and I couldn’t do anything about it. So, I went in, saw him, and was scared to death.”

“I think they withheld a lot from me because they weren’t sure how I would handle it, and then for me not being able to handle it, then for my sister to see me. I think they didn’t want me to get upset or emotional.”

A small number of siblings (18%) believed that their parents had insufficient information themselves, not having adequate information until after treatment began.

Focus group discussion supported the majority view, that the amount of information presented to them at the time of diagnosis was not adequate. Group members also identified two of the same reasons for the absence of information: their maturity level and parental protectiveness.

In contrast to their children’s views, the majority of parents felt that they had presented enough illness-related information during the time of diagnosis (60%).

“There was nothing else I could have told her. She knew everything, every single detail right down to blood test results. Even when they didn’t understand it, we would break it down for them. This was a family thing, not an isolated thing. There is absolutely nothing more I could have told them.”

They attributed the same three reasons for the lack of information: maturity level, needing to shield them, and a lack of information to share.

“She was young, and I don’t think she could have taken on anymore information at that time. I think we tried to protect them, but often times, they picked up more than we were willing to give.”

Type of Illness-Related Information

Sixty-four percent of the siblings reported that it would have been helpful to know more details about the type of cancer, such as whether or not it was inherited or contagious,

if it was life-threatening, and where the cancer was located in their body.

“I knew leukemia was cancer, but I didn’t know what kind of cancer it was. I had no clue what blood cell counts meant and what was normal, and that if it was high it was bad or anything like that.”

In addition to wanting detailed information about the illness, some siblings desired either information about the treatment procedures and the common associated side effects (36%), or about all the family changes that were taking place (18%).

“I didn’t know if they were going to have to take something out of him, or how they treated cancer at the time. I thought it was just radiation. I had no idea.”

“I wanted to know what was going on and where he was all the time...and where my parents were going. I was always with my grandma, for almost three years of my life. I began to call her ‘mom’ because I didn’t know where my mom was.”

The desire for additional information on treatment effects was supported in focus group discussions. They also discussed the merits of having received an explanation for why their sibling looked sick on some days, but not others.

Nearly all of the parents stated there was nothing else they would have told the siblings (90%). The one parent, who differed, said that she would have reassured her children that the cancer was very treatable.

“I would have reassured them that she would probably be ok. You know, the knowledge that just because she has cancer doesn’t mean a death sentence. I took it as a death sentence.”

Sibling Involvement in Treatment

Half of the siblings claimed during interviews that they were actively involved in their brother or sister’s care, either spending time in the hospital or participating in treatment at home.

“I was involved quite a bit. I would keep him company in the hospital overnight on the weekends. There wasn’t a lot I could do, but I was happy that I could spend time with him...play games with him at night.”

The remaining 30% were uninvolved in treatment, due to either the absence of an expectation to participate, or the need to protect avoid the sibling's compromised immune system.

"I was always told not to go around him because he was sick, and I thought I would get him sicker or give him germs. So, I thought I was this big germ person."

Twenty percent reported being somewhat involved in their brother or sister's treatment.

Most parents stated that their child had been actively involved (56%), some were moderately involved (33%), and one was not involved.

"Well, this happened at the beginning of the school year, and he was going in every day during school hours for treatment. So, I think it was a matter of she was in school and had her own life to keep up with."

The Significance of Being Involved in the Patient's Treatment

A majority of siblings reported that it was (or would have been) important to participate in their brother or sister's care (80%).

"We learned how to clean her broviac. It lessened our fear to know what to do in case our parents weren't there in an emergency...to know what to look for and what to do helped a lot! We were not terrified about anything. We were not scared of her cancer at all. We weren't scared about her broviac or her polls. We could work all the machines. We could even fix them before the nurses came in!"

Only 20% were either unsure about wanting to be involved, or were relieved that they had limited involvement.

"I saw pictures of him when he was on treatment, and it looked kinda scary. I don't know if I would have wanted to be there. It might have been kind of emotional...maybe it was good in a way (not to have involvement) because I know a lot of girls that are scared of the hospital because it brings back a lot of bad memories. I don't really have any bad memories because I was never really there when he was in bad condition."

The majority of focus group members saw their involvement as a positive experience; it reduced their fears and contributed to their understanding of the treatment

process. One group member believed that participation could generate additional fears. This comment prompted a discussion about the degree of preparation they experienced prior to seeing their hospitalized sibling. Half of them had either a parent or staff member explain what they could expect to see; the others received no such preparation. Although most were in agreement that preparation was a critical factor, they also felt that the full impact of the experience defied description.

“There is really no way to prepare actually. I mean, you can’t explain what you are about to see when one of your family members looks that way...with no life in them.”

Ninety percent of the parents saw sibling involvement as a positive experience, and sometimes even a necessity for the healthy child.

“I didn’t have a problem with that (being in the hospital with the sick child) because the hospital was so good. They probably would have alleviated some of her fears.”

Summary of Research Question One

More than half of the siblings felt the information presented was not sufficient, while over half of the parents felt it was sufficient. The types of additional information siblings desired included diagnostic details, treatment effects, and impact on family. However, parents viewed additional information as unnecessary. Both siblings and parents rated approximately half of the siblings as “very involved,” and the remaining ranging from moderately involved to uninvolved. Nearly all of the siblings and parents felt it was important for the sibling to participate as much as possible.

Research Question Two

When healthy siblings of post-treatment pediatric cancer patients look back to the time of their sibling's diagnosis, what do they report as being their most significant concerns?

The siblings and parents were asked to discuss the sibling's initial concerns when their brother or sister was diagnosed with cancer. Table 6 summarizes the responses regarding siblings' concerns at the time of diagnosis.

Initial Concerns at Time of Diagnosis

Nine out of the 11 siblings directly reported they were initially concerned about their sibling's survival.

“(I was concerned about) her dying. For anybody, that is the first thing you are going to think about. What if she doesn't make it. That is what people think...what will I do without her?”

“I remember overhearing a conversation that my parents were having, and them saying, ‘What if we can't get him through this?’ So, I didn't know if he was going to die. I never knew. I didn't expect it, but I would wake up and think, ‘Oh my gosh, I wonder if he is going to die today.’”

One sibling reported being initially concerned about her own health, while the other sibling reported that her first concern was related to her brother missing his free time during summer vacation.

The siblings in the focus group all acknowledged that their initial concern centered around their sibling's survival. No other initial concerns were mentioned.

Similarly, the majority of the parents (i.e., 90%) stated the sibling was concerned about their brother or sister's survival.

Table 6

*Percentages of Responses to Most Significant Concerns
at Time of Diagnosis*

<i>Category</i>	<u>Percentage</u>		<u>Response</u>
	<i>Sibling</i>	<i>Parent</i>	<i>Group</i>
First Concern			
- Patient's survival	82	90	S
Other Concerns			
- Family emotional/financial stability	64	30	
- Contagion of illness	27	30	
- Patient's daily functioning	18	20	
- Losing parental attention		10	

S = "Salient" - majority of group endorsed

P = "Present" - some (or half) of group endorsed

NP = "Not Present" - question was asked and group did NOT endorse

Blank = question not asked directly and/or was not addressed by group

“It was pretty obvious, he was worried that she was going to die. The only kid he knew with leukemia was our friend, and he died 14 years previous. We were all concerned that she would struggle for two to three years, and then lose her. So, he was worried that since she had leukemia, she was going to die.”

One parent stated that the sibling’s initial concern was not her brother dying, but rather the changes in the family that took place.

“I think she just felt like he was going to get well. If I were to guess, I would have to say that she was worried about changes at home. You know, I had to be gone at the hospital a lot with him, and her dad had to take over some of my duties. We all lived together, but had specific duties that changed around a bit.”

Other Concerns at Time of Diagnosis

Sixty-four percent of the siblings reported concerns relating to family stability (either emotional or financial).

“I was worried about what would happen to the family. This is a major thing. It could have changed like that! People can change when something that extreme happens to your family...they change. And, I was worried about what would happen...like, we would grow apart.”

“We didn’t know how we were going to pay for it. So, we were kind of concerned because my dad would have to miss a lot of work, but my aunt took us over during the day after school, and then my dad picked us up there.”

Other concerns noted included being afraid of catching the illness (27% reported), and concerns about the day to day functioning of the patient (18% reported).

“When I first went to the hospital, I thought I was going to catch it too, and that would happen to me also. So, I didn’t want to be that close to her at first. I didn’t want to go sit on the bed with her. My parents would always tell me to come over to her, but I wouldn’t want to. Then they explained to me that it wasn’t contagious.”

“I was concerned that she was always sick and people at school didn’t know what was going on. So, I didn’t know if people would hear stuff, and then would talk. I was afraid for her to come back to school and not have hair...and then the kids would tease her.”

When the parents were asked about other concerns the siblings had after diagnosis, 30% stated the sibling was concerned about the family's emotional stability, 30% stated the sibling was concerned about the cancer being contagious, 20% reported concerns related to the patient (e.g., losing hair, limb), and 10% reported concerns related to missing school, and losing parental attention.

Summary of Research Question Two

The overriding theme from the sibling interviews, focus group, and parent interviews was directly related to the survival of the patient as the initial concern. Other concerns reported by the siblings primarily revolved around family stability, and then contagion of the illness and patient's daily functioning. Other concerns as reported by parents involved family stability, contagion, patient's functioning, and loss of parental attention.

Research Question Three

When healthy siblings of post-treatment pediatric cancer patients look back on their sibling's illness, what aspects of the whole cancer experience do they perceive as being the most salient?

Siblings were asked to discuss the most difficult aspects of having a brother or sister with cancer, as well as the changes that occurred in their lives during this time. Table 7 summarizes the areas where children and parents reported salient changes.

Most Difficult Aspects of the Cancer Experience

When asked directly about the most difficult part about having a brother or sister who had cancer, over half of the siblings (i.e., 60%) answered with statements regarding the sibling's prognosis.

Table 7

*Percentages of Sibling, Group, and Parents Who Endorsed Salient Changes of
Cancer Experience*

<i>Category</i>	<i>Percentage</i>		<i>Response</i>
	<i>Sibling</i>	<i>Parent</i>	<i>Group</i>
Most Difficult Aspect of Having a Sibling with Cancer			
- Uncertainty of patient's prognosis	64	60	S
- Dealing with support/sympathy from others	18		
- Lack of interaction with patient in hospital	18		
- Dealing with family changes		20	
- Survival guilt with other siblings		10	
- Physicians providing percentages re: prognosis			S
Changes in Sibling's Life			
- Family			
- Extended family members/increase in stress	90	90	P
- Increase in responsibilities at home	90	40	P
- Affect			
- Jealousy/anger re: loss of attention	90	40	S
- Overall irritability/anxiety	73		S
- Social Relationships			
- Spent less time with peers	73	30	S
- Strained relationship with peers	36	30	S
- School Functioning			
- Increase in school absences	29	20	
- Decrease in grades	18	20	

S = "Salient" - majority of group endorsed

P = "Present" - some (or half) of group endorsed

NP = "Not Present" - question was asked and group did NOT endorse

Blank = question not asked directly and/or was not addressed by group

“I think the most difficult part is never knowing if her cancer will reoccur...because if it reoccurs, it goes to her lungs.”

“I guess it is always knowing that it may never really be gone. Being afraid that it could come back.”

A small number of responses identified the most difficult aspect as dealing with receiving support from others, and missing the patient while they were hospitalized for treatment.

“(The most difficult thing is) everybody sympathizing and saying they understand when they don’t. It also bugs me when people say ‘I am so sorry.’”

“(The most difficult thing was) not having her there...especially when I was becoming a teenager.”

It is important to mention the numerous, unprompted comments that siblings made during the individual interview regarding the strong emotions they experienced during the patient’s diagnosis and treatment. A majority discussed their intense fear.

“I remember having nightmares because he had really bad screaming attacks due to his headache. When he was diagnosed, I went in, saw him, and was scared to death.”

“When I saw my dad cry, that was scary. I knew something was wrong at that point...that it was serious.”

Additional emotions described were confusion, sadness, and anger.

“When he was diagnosed and went in for surgery, I was sent to my grandmother’s house. Everyone was so emotional and everything. That really scared me because my parents were not making a big deal out of it, but everyone else was...so I was really confused.”

“I got to see him, but it really hurt me because he was just lying there in the hospital bed in the house, and couldn’t do anything...not even talk. He would just lie there and sleep. Whenever he was awake, he looked like a zombie...and that hurt.”

In the group interview, all comments regarding the most difficult aspect of the cancer experience fell in the general category of concerns about the patient’s wellness (i.e., the unknown prognosis of their sibling), waiting to see what would happen with

treatment, and watching the sibling suffer. A salient theme in the group interview was siblings' dislike of physicians giving "percentages" about their sibling's prognosis.

"My problem was the doctor kept giving us numbers...like a life expectancy, and he would keep outliving that. I was just waiting for that luck to run out."

"It is like everyday you wake up and think, 'oh, today is the day,' but it is not, so you do it again the next day and the next."

The siblings' intense emotions during their brother or sister's treatment were also discussed during the group interview, with fear again emerging as the primary emotion. However, despite their fears, they became acclimated to their siblings' altered appearance, and did not expect them to look normal anymore. This acclimatization was not mentioned in the individual interviews.

Consistent with the siblings' self reports, parents also saw patient wellness as the primary difficulty their children experienced (60%). They stated that their children had a difficult time dealing with the uncertainty of their sibling's prognosis.

"(The most difficult thing for her) was not knowing what was going to happen from one minute to the next...constantly worried when she was at home, if she would have to go back to the hospital because she spiked a fever."

Another 20% viewed family changes as the most difficult experience the sibling faced.

"I would say (the most difficult part for her was) separation from the family. It seemed that we were always separated from the other kids. When we were at UCLA, the kids probably went six weeks or so without seeing Bobby or I...That was probably the most difficult thing."

One parent felt that the sibling's greatest difficulty had been dealing with other siblings who had lost a brother or sister when her brother was still alive.

"She had a lot of trouble dealing with the fact that her brother was alive and Cindy's brother wasn't. That was really difficult for her. She would try and comfort her and then sometimes be afraid to comfort her. She felt so guilty."

Several parents also made unprompted comments about the sibling's affect. Many of the comments dealt with feelings of fear and sadness.

“They came in and didn't say much. I just wanted her to smile and reassure them, but they were quickly rushed out...except for Ryan. He lingered for a while. He leaned against the wall and just sobbed. He then said, 'I can't lose her mom.' Then he kept asking how we could save her.”

Changes in Sibling's Life

Siblings were also asked to discuss the various changes that occurred after their brother or sister was diagnosed with cancer. The most frequently reported changes were alterations in family structure, as caretaking roles shifted to extended family members.

“My parents would always go and be with her (in the hospital) and we would go to my cousin's house. We stayed there for 3 weeks or something. Right before school started. I didn't like it. I got sick of it. And then we finally got to come home with my dad, but we were at home by ourselves all day...waiting to find out stuff.”

Three of the parents (27%) divorced during the patient's treatment. This highlights the degree of stress that families endured after the diagnosis of cancer, as well as the changes in relationships among family members.

“You could really tell there was a lot of tension around the home. Me and my parents fought a lot, and times would get really bad that I wouldn't want to be at home...and I would do whatever I could to get out. It wasn't fun. It really pulled us apart.”

Another family change was the increase in the siblings' responsibilities at home. All but one of them stated how they either “took over” the parent role in terms of day to day responsibilities, or felt they were required to be a strong role model for their younger siblings.

“My responsibilities changed a lot. I didn't go out with my friends anymore. I stayed home and helped around the house. I had to watch what I did because being the oldest boy in the house, I had to be the best example. I had to really take charge of the house when my dad was gone. I had to do everything.”

“I became the mother...helping my sister cook and do stuff. We would all help out my dad because it was hard for him. He had to play the dad and the mom.”

Two of the siblings mentioned feeling responsible for aspects of the patient’s treatment.

“I remember when I was 10 and there was something wrong with her shunt. It was the pressure in her brain, and they thought she was probably having seizures at night. So, I had to sleep in her room for 6 months and watch her at night.”

Again, in this portion of the interview, siblings discussed the difficult emotions they faced during this time. Nearly all of them reported feeling jealousy or anger about the lack of attention they received.

“I was a little self-centered because all of a sudden they weren’t paying as much attention to me. I was really jealous, and then mad at myself for being jealous. All of a sudden, I really wasn’t in the picture anymore. I felt kinda out of the picture. I used to get asked by my cousins to come over and spend the night...and then all of a sudden, people stopped asking. I don’t know why. They were paying more attention to my brother, and didn’t want me to come with them.”

“When she was in the hospital, we went through this thing where we wished it was us that were sick so we would get all the attention. I mean, she had all these balloons and the Make-A-Wish and all the toys. I wished it would happen to me so I can get all those things. My sister was the oldest, my little sister was the youngest, and then my other sister had cancer. I was left out! The only person left out.”

Seventy-three percent of the siblings discussed feelings of increased irritability, anger, worry, or insecurity during the initial phases of treatment.

“I would be mad all the time. The big thing was why did it have to happen to MY family! I didn’t sleep very well. I was not a happy kid. I pretty much just kept to myself for a long time.”

Nearly half of the siblings talked about how they could not share their true feelings with anyone during this time, especially their parents due to the stress already apparent.

“I used to bottle my feelings inside. I still remember those feelings...how scared and hurt and worried I was, and how I thought I had no one to talk to. It was hard.”

“I pretended there was nothing really wrong. I held it in because I knew he was sick, and I understood why everyone was being so much nicer to him, but it was still really hard. I felt it would just complicate things, so I just held everything in...all those emotions and, you know, why I was angry. I felt bad though because I was angry. I thought there was something wrong with me for feeling this way.”

In addition to the family and affective turmoil, the siblings reported changes in their social relationships. Many spent less time with their friends after their brother or sister was diagnosed (73%). Some siblings attributed this to being too busy either at the hospital or taking care of needs at home, and for others, to the fact that they either moved away from their friends to be closer to the treatment center, or lived in the homes of extended family members. Despite social changes, nearly half of the siblings found that their friends continued to be supportive and available. However, this wasn't the case for a few who experienced disappointment in their former friendships.

“I remember not spending that much time with friends that whole year. I lost one friend, and I think that was a direct result from that. I didn't tell my friends about it (diagnosis/treatment) because I didn't want them to feel sorry for me. I had one friend who asked me if my family had a wish from the Make a Wish Foundation...and then she said she wished she had cancer so she could do that. I never had the same group of friends after that. I didn't feel comfortable talking about it with them.”

The third area of change was school functioning. Surprisingly, the majority of siblings (71%) reported that they didn't miss many school days and 82% maintained the same school grades, although some felt that their teachers were more lenient due to their family situation.

“I started doing really bad in school...that whole year, but the thing was, my teacher felt so bad for me that she gave me the grades anyway. Like, I didn't do homework at all. I didn't do anything. I was just mad all the time.”

Many of the siblings, however, discussed how it was very difficult to go to school at times, especially when they were worried about their sibling.

“It was stressful going to school when all you could think about was if he was going to be ok, and what am I going to do if he is not there the next morning. My mind was so confused. It was hard to get my thoughts together and concentrate on one thing for five minutes.”

“There were sometimes when I just didn’t want to go to school because I wanted to be there with him. There were some days when he couldn’t go to school. My parents would really have to make me go.”

In the focus group, siblings also discussed changes in social and familial arenas, as well as the intensity of their emotions. As a group, they agreed that they spent less time with their friends during their sibling’s treatment. The majority looked at their friends differently after diagnosis. They related stories about friends who were afraid to be around them, or were “superficial,” or were cruel.

“Some of my friends started to make fun of him. Sometimes we would get into an argument, and then they would make some cheap comment about how he looked or something.”

Group discussions addressed a variety of family changes: the painful effects of absentee parents, the lack of family cohesiveness, and the shouldering of responsibility for their younger siblings. They also discussed how some families were torn apart, while others became closer. No changes in school functioning were mentioned in the group at all.

As in the individual interviews, siblings in the group described the strong emotions surrounding their siblings’ illness, but feelings of guilt was a much more pervasive theme. Siblings felt guilty for multiple reasons: wanting attention; not spending time with their sibling in the hospital because they were afraid; and being embarrassed or ashamed of their sibling when treatment side effects surfaced.

Parents viewed the changes in their children’s lives somewhat similarly, although most focused on family impact, less than half mentioned affective, social, or school

changes. Nearly all of the parents mentioned the structural changes in the family that occurred after the cancer diagnosis.

“My mom called Children’s Hospital of LA, and they had a life flight ready to take him. I didn’t have clothes or anything. I didn’t get to go home. I had a new baby and the two other kids at home. We headed out to California. I didn’t see the kids for a month and a half. They came for a quick visit just to say hello. Dan had to keep up with his job because we needed to keep the insurance. So he kept working, and my sister-in-law pretty much raised my new baby and helped out with the other two. She became mom. I mean, our family was split apart in several directions. It was probably one of the worst case scenarios I can think of.”

Interestingly, none of the parents commented on changes in the actual relationships among family members, as the siblings had done. Only four parents recalled an increase in their child’s responsibilities, either in household chores or taking on more of a “parent” role. In these cases, the children were older than their ill sibling.

“When I was in the hospital with Holly, my oldest daughter had to do the cooking and Grace did the laundry. They basically took my place.”

“I do feel guilty about making him another adult in the family at the age of 12. He took on the parenting role for the other kids. His other brother was equally as helpful, but because he was the oldest, that was his role. There were many times she was sick and we had to get her to the hospital. I was acting really stressed, and he would say, ‘Mom, you know Laura is going to be ok.’ All of a sudden, his words completely comforted me and I had to remind myself, you are the parent, this is your child, you need to be comforting him.”

Three parents reported that responsibilities did not change at all once their child was diagnosed and treatment began.

A minority of parents identified changes in areas other than family: emotional impact, (40%) social relationships (30%), and school functioning (20%). A divergent view of school emerged from the parents. Whereas some of the siblings felt teachers were lenient, some parents felt otherwise.

“They had some problems with teachers...like when I would write to please excuse them from their homework because it was a hectic night, some of their

teachers would come down on them. I told them that they would have to stand up for themselves because I couldn't be there for them every minute. If that teacher makes you mad, I told them they should open their mouth and say something to them. I didn't want to come home and find them all upset because of a teacher or anything else."

The minority of parents who felt they had not given adequate attention to their healthy child described the impossibility of their dilemma, seeking to justify their actions.

"So, most of her childhood, it wasn't like she was neglected, she was just second fiddle. There was no choice. It broke my heart that I couldn't be with her when I was with Kathleen in the hospital. There was nothing I could do. The needs of one outweighed the needs of anything else. There was nothing that was going to pull me away from that hospital."

Summary of Research Question Three

The majority of both siblings and parents felt the most difficult aspect of the cancer experience was the uncertainty of the patient's prognosis. Both groups believed that the most salient changes occurred in family life. However, not as many parents reported changes in other areas: affect and social relationships, as did the siblings. It appears that most parents were unaware of their children's reported difficulties with increased home responsibilities; limited time for social opportunities; and feelings of jealousy, anger, irritability, anxiety, and guilt.

Research Question 4

What issues or concerns continue to be prominent to siblings of pediatric cancer patients years after their sibling's diagnosis and treatment?

The siblings were asked to discuss their current concerns surrounding their sibling, as well as discuss how their lives have changed since their experience with cancer in their families. Table 8 summarizes these responses.

Table 8

Percentages of Responses to Sibling's Current Concerns and Overall Functioning

<i>Category</i>	<i>Percentage</i>		<i>Response</i>
	<i>Sibling</i>	<i>Parent</i>	<i>Group</i>
Current Concerns			
- Patient's overall functioning	70	44	S
- Patient relapsing	60	50	S
Current Relationships			
- Parent(s)			
- Closer relationship	90	80	
- Strained relationship with at least one parent	40	20	
- Patient			
- Closer relationship	75	90	
- Continue to feel responsible for patient	60	67	S
- Peers			
- Prefer siblings at camp as friends	36	40	
- Have chosen different friends	18		
- Closer with same peers	10		P
- Distant with peers	10		P
Affect			
- Guilt (leaving patient, seeking attention, how treated patient, siblings who have lost brother or sister)	64		S
- Anger regarding changes in sibling's life	30		

S = "Salient" - majority of group endorsed

P = "Present" - some (or half) of group endorsed

NP = "Not Present" - question was asked and group did NOT endorse

Blank = question not asked directly and/or was not addressed by group

Current Concerns

Sixty percent of the siblings reported ongoing concerns about their sibling's cancer reoccurring.

"I worry about her survival because of the whole thing about how she wasn't supposed to make it to be a teenager...and she is a teenager now. Yea, it really scares me that it is going to come back really soon. It really scares me. I think I will always worry about that."

"I worry about her relapsing especially when my mom tells her she looks tired...little things like that, we get kind of worried. She had a scare a couple of years ago when she had a weird thing in her mouth...they said it was from chemo, but it wasn't cancerous. So, little things like that are scary."

Siblings also discussed worrying about their sibling's ability to function independently in society. Seventy percent of the siblings reported they are concerned about physical and/or cognitive long-term effects from their sibling's cancer treatment, and how they may not be accepted by their peers.

"I worry about him being accepted by other kids. He has to take growth hormones and is not as tall as the other kids in his class. And he has a learning disability from the radiation. And his teeth, he has to get dentures when he turns 13 and all his teeth fall out, because the radiation killed the adult teeth. When he is in 6th grade, he has to start getting hormone shots to get him through puberty. And he cannot reproduce at all. I worry about no one wanting to marry him because of that."

"Well, I do have one concern...because of all the radiation, her brain...she was way ahead in reading and math. And now she is way below grade level. She could read better in kindergarten than she can now because of the radiation. So, she has a tutor, and that is really hard on her. I know some of her friends make fun of her...so, I am worried about that."

Focus group discussions supported the primary theme of worrying about their sibling relapsing. Group members also identified other concerns including how others treat their sibling, as well as the long-term effects of their sibling's treatment.

In terms of the patient's overall survival, half of the parents stated the siblings continue to worry about relapse, while half of the parents think the siblings have moved past this concern.

"I think that (relapse) is something that will always worry them, but as siblings, they treat him like he is one of the other kids...more now."

"I don't think they worry too much anymore. I don't think there is that fear of Abby not being here anymore. I think they got to the point of 'you are going to make it.' They said she would never see her teenage years...and the fact is she is a teenager now."

Other concerns reported by the parents included the siblings worrying about how the patient will be treated by their peers (22%), as well as worrying about the long-term effects of the patient's treatment (22%).

Current Functioning/Relationships

Relationship with parents. Nearly all of the siblings reported a closer relationship with one or both of their parents since treatment has ended.

"I have actually built a better relationship with my mom. There was always this thing before where I thought, 'you always left me alone' and I felt neglected...even as I was getting older and understood it. But now, I think I have built a better relationship with her. I wouldn't change that for the world now. I mean, it took a long time to get there... almost 10 years to make it what it is now. It was so worth it."

Four of the siblings discussed how going through the cancer experience negatively affected their relationship with one of their parents.

"I think it brought me closer to my dad, but further apart from my mom. She doesn't really like to show emotion. She keeps it all inside. I guess that one year screwed her up. She puts up a wall and doesn't let anyone in. That is hard because she is my mom, and you should have emotions."

Focus group discussion did not focus on the current relationship between the siblings and their parents. Similar to the siblings' in the individual interviews, the

majority of parents (i.e., 80%) reported a closer relationship with the sibling since treatment has ended.

“For a while it made us distant. I know now looking back that I should have given her more attention. However, now she clings to me more now that she is maturing. We have become much more close in the last 2 years. I always tell her there is nothing she cannot talk to me about, no matter what.”

Two of the parents stated that the cancer experience negatively affected their relationship with the sibling.

“It was positive for their father, but negative for me. I missed out on a couple of years. We are not as close as we were before. They throw it in my face with ‘you were never here for us’ even though they understand why. But, whenever they get mad at me for something, it comes out. They are just really bitter because the cancer took us away from them. Our family has never been the same.”

Relationship with patient. Seventy-five percent of the siblings reported a closer relationship with their sibling, who was sick, years after treatment has ended.

“Well, I think it brought me a lot closer to him because it helped me realize that I may not have been able to see him again...so, I figured I better make time to spend with him and to let him enjoy life, whatever time he has left, however long that may be.”

Twenty-five percent of the siblings reported that their relationship with their sibling has become strained since their experience with cancer and now that treatment has ended.

“I think we have grown apart because she is getting this attitude that she can do whatever she wants. And my mom tries not to say anything to her about it, but come on! You don’t use your illness as a factor to get away with stuff. That makes me so mad!”

“Even still to this day, I am not comfortable being around my brother. I am not that close with him because he was never around. Now I don’t really want him around. I feel like there is this space there that can’t be filled...like a void. You know, he wasn’t supposed to survive. So, Bobby is a miracle actually...but miracles can be pretty annoying!”

Many of the siblings discussed how they continue to feel “responsible” for their sibling’s well being, even years after treatment. Specifically, 60% of the siblings reported

either feeling protective over their sibling, especially towards other people, or feeling the need to physically take care of the needs of their sibling.

“I am pretty protective (over him). If you want to mess with one person, you mess with the whole family. If you mess with the family, you better run!”

“Ok...she is my older sister, but I have to act like hers because I have to watch over her. I feel like I have to watch over her. People don't see that, but I feel that. She is my sister, and if something happens, it is all over. It is just something that I have to do. I had to grasp a lot of things really fast.”

Related to many of the siblings feeling responsible for their sibling's needs and well being, was the issue of feeling like they have sacrificed their own life by continuing to be a caretaker to their sibling. Two siblings described this experience.

“It makes me sad because she hangs out with me. I mean, you can only have so much of a person. I go to school with her...I go to lunch and see her...and then after school I see her. I love her to death, and am always going to be there if she wants to hang out with me. But it is really hard on me...really hard on me. I don't have my own life now. I mean, I do, but I really don't. It is always me and Kathleen.”

“My life revolves around my sister. It is hard, really hard. That is mostly the reason why I wanted to leave (for college)...to have my own life because a lot of times I can't go out with my friends or just drive in the car by myself! I mean, just to be alone because I am never alone. It is like I am not allowed to be or something. I want to get away just so I can be on my own and live my own life. I need to get away from the family, but when I do, I don't know what they will do. I can leave my friends, I can leave my life...but the hardest thing is going to be leaving her. I really don't know what they will do.”

The siblings in the focus group did not specifically address the status of their relationship with their now healthy sibling. However, discussions did focus on how the siblings often feel they have sacrificed their own lives in order to take care of their siblings (even years after treatment), as well as often feeling guilty for leaving them.

Ninety percent of the parents reported a close relationship between the sibling and the patient currently. One parent stated that there is more tension in their relationship than prior to the patient's diagnosis and treatment.

"I think it initially brought them closer, but I think it has gone both ways...distanced them also. She gets incredibly irritated with him, but also defends him. I think she gets mad at us because we don't demand as much of Bobby. Sometimes she will just say, 'I do love you Bobby, but there are things that you do that drive me crazy!'"

Similar to the individual interviews, many of the parents discussed how the siblings continue to feel responsible for the patient's well being. Specifically, 67% of the parents reported that they think the sibling is protective over the patient.

"She became a parent...very protective. Just recently, a boy gave her brother a hard time. Emily was real defensive and stuck up for him. Almost like, 'I can talk about my brother, but you better not!'"

"She has been like an adult since she was 10. She has always been in 'protect' mode. Even now, if I do something like get mad at her sister (patient), she will stand up for her."

Only one parent mentioned how the sibling has 'sacrificed' her own life to take care of her sister.

"She never knew what it was like to be the youngest because she never felt that way. And if you ask me if she has a problem with it, she does...about not being independent, not having her own friends, her own class. It has always been that way."

Relationships with peers. The siblings' responses to changes in their social relationships were variable. Two of the siblings reported having different friends now, and four of the siblings stated they preferred to have other siblings at camp as their close friends. One sibling reported a closer relationship with her current friends, while one sibling stated she is now more distant with her friends because she is afraid to get "close"

to others. In addition, several of the siblings discussed how they often become frustrated or irritated at their peers for complaining about insignificant things.

“I don’t know if this is right, but when people come to me with their problems, it is like...I mean I try listening, and the problems are probably big to them, but I am just thinking, ‘Oh my goodness, try dealing with my stuff and then come and tell me about it.’”

In the focus group, a few of the siblings discussed, and many of the group members agreed, how their peer relationships changed after their sibling’s treatment, either due to some of their friends teasing their sibling, or realizing that their friends were “superficial.” In addition, half of the siblings discussed how they are more “open” with their friends and take more risks, while half of the siblings stated that they do not open themselves up as much to their friends for fear of becoming hurt.

Only four of the parents commented on the sibling’s current relationships with their friends. Specifically, these parents reported that the siblings feel much closer to their friends at camp, than the friends they have at home.

“Well, camp has been so important because they cannot just discuss things like that with their friends at school. They have a special bond with camp friends because they can really relate to one another. Their friends at school can listen, but it is not the same because they cannot really understand like someone who also has gone through it.”

Overall Affect

When discussing siblings’ perceptions of the salient aspects of the whole cancer experience years after treatment has ended, it is again important to mention the numerous, unprompted comments that were made regarding the siblings’ affect. For example, 64% of the siblings discussed continued feelings of guilt surrounding leaving their sibling behind, for their desire to receive more attention from their parents, for the way they treated their

sibling during treatment, and regarding other siblings who lost their brother or sister to cancer.

“I take care of her and take her a lot of places. If she ever has to stay home, I feel really guilty when I go out with my friends and then she is just home. I feel guilty all the time. And then a lot of the time, she asks me to go out with us. I mean, I take her, but just one-on-one or with some of my good friends. Not when I am going to a party because I am afraid people will make fun of her.”

“Well, I was kinda selfish because I wanted my parents to pay more attention to me. Now that is so hard for me! I feel bad now because I wasn’t the one who went through it, so why am I so upset all the time. I feel guilty coming here (camp) like I am getting all this attention and sympathy, but I shouldn’t be the one getting it!”

“Another hard part is coming here and hearing about another person’s brother or sister passing away. That is so hard, you know because I feel guilty. Like, I am glad it was her brother and not my sister...and that is so bad to say!”

Additionally, 30% of the siblings reported feeling residual feelings of anger or resentment surrounding changes in their lives as a result of the cancer experience.

“It is hard for me because I feel like he (dad) doesn’t know how to deal with her (patient). I don’t understand how he doesn’t know how to treat her. Like he should know...so, how does he not know! Like my dad gets mad at my sister when my step-mom gets mad at her...and it is so hard because he doesn’t like to see his wife frustrated. I know I can’t change it, and I just have to stay out of it.”

Finally, the siblings reported overall emotionality related to the whole cancer experience, even years after treatment has ended.

“I used to bottle my feelings inside...so I kind of left it in me, and it just tore me apart! That is why it is so emotional for me still because I still remember those feelings...how scared and hurt and worried I was.”

“I am still a really emotional person...and anytime I start thinking about all that stuff (treatment), it will just hit me and it is so hard for other people to deal with.”

Emotionality was also very salient in the focus group. Issues presented by the siblings primarily centered around feeling guilty for leaving their now healthy sibling, for

wanting more attention from their parents, and for other siblings who have lost a brother or sister.

“Your parents are trying so hard to help them (patient). You feel guilty for wanting attention because they were the one who was sick.”

Additionally, many of the siblings in the group discussed how they have never expressed their feelings surrounding the patient’s illness and treatment.

“That is why it is so emotional now, because we are remembering how it felt at that time.”

“Yes (it is good to get it out now) because you bottle it up for so long. It is like you are allowed to cry now because no one is going to look down on you.”

“The minute I sat down with you I started crying. I don’t know why. I just never told the whole story before.”

None of the parents discussed how the siblings may have residual feelings of guilt or overall emotionality relating to changes in their lives as a result of their sibling’s illness and treatment.

Summary of Research Question Four

Both the siblings and parents report that the most significant concern for the sibling currently relates to the patient, both with the possibility of relapse, as well as with their ability to function independently in society due to the long term effects from the treatment. In terms of the sibling’s current relationships, the majority of both the siblings and parents report a closer relationship between the sibling and at least one parent, as well as a closer relationship between the sibling and the patient. Socially, half of the siblings reported a closer relationship with their peers, while other siblings either reported no change or negative changes. In terms of current affect, the majority of the siblings focused on feelings of guilt for either leaving the patient to go to college, for wanting attention from

their parents, for how they treated the patient during treatment, or for other siblings who have lost a brother or sister to cancer. Overall emotionality was also apparent among the siblings, which centered around feeling like they have “bottled up” their feelings surrounding their sibling’s illness, and now feel the need and desire to express them. It appears that most parents are unaware of the siblings’ residual feelings of guilt and overall emotionality.

Research Question Five

According to siblings of post-treatment, pediatric cancer patients, what coping strategies and interventions are perceived to have been the most helpful during the early phases of treatment, as well as throughout their sibling’s illness?

Table 9 summarizes coping strategies used by the siblings. Interventions that siblings and parents viewed as helpful are also provided.

Coping Strategies

The most common coping strategies used during their sibling’s illness and treatment included distraction (67%), positive thinking (36%), and expressing feelings (36%).

“I tried to do things to distract myself like playing or hanging out with friends...because there was only my mom, and she was always in the hospital. So, I would go over to my friends house and try to have fun.”

“I thought, you can’t be sad about it...you can only hope. Hope and faith are major things.”

“We talked about it as a family...like, what she would have to go through and stuff. I guess I also talked to a few teachers about it.”

Other coping strategies used included praying (27%), keeping feelings to themselves (27%), crying (18%), keeping things normal at home (18%), and doing something productive to help the patient or other siblings (18%) (e.g., making crafts for the patient).

Table 9

*Percentages of Siblings and Parents who Endorsed Previous and Current Coping**Strategies and Helpful Interventions*

<i>Category</i>	<i>Percentage</i>		<i>Response</i>
	<i>Sibling</i>	<i>Parent</i>	<i>Group</i>
Coping Strategies Used at Time of Diagnosis			
- Distraction	67	30	
- Positive thinking	36	50	S
- Expressing feelings	36	30	
- Prayer	27	30	
- Hiding feelings	27	30	
- Crying	18		
- Maintaining normalcy	18		
- Activity to help patient	18	30	
Coping Strategies Used Currently			
- Expressing feelings	73	60	
- Positive thinking	36	40	S
- Prayer	18		
- Take anger out on parents/peers	18		
- Distraction	10		P
- Medicine/Somatic complaints		30	
- Exercise		20	
- Seeking information		20	
Most Helpful Coping Strategy			
- Expressing feelings	100	60	S
- Positive thinking	36	40	S
- Prayer	10	50	
- Seeking information		40	

Helpful Interventions			
- Receiving sufficient information about diagnosis/treatment	91	50	S
- Sibling support (support group/camp)	91	80	S
- Help from church	55		
- Someone to confide in	45		S
- More attention from parents	27	30	S
- Professional intervention		30	
- No life expectancies from physicians			S

The siblings were also asked to discuss how they cope with their emotions currently, whether about the patient, or when they become upset by something in their lives. Interestingly, only one sibling reported using distraction as a means of coping with their current concerns. The most common coping strategies currently used included dealing with their emotions directly (e.g., by either talking to someone about them, writing them down, or “facing their problems”) (73%), positive thinking (36%), and prayer (18%).

“I write a lot of poetry. I have like over 300 poems...but, most of them are not happy poems. It is a way to get stuff out.”

“I am better about talking about it now. I can talk to him (i.e., patient) about it because I know he is more comfortable about talking about it. If I keep it all inside, it just comes out all of a sudden one day, and then I really regret the way it came out. Sometimes I will take it out on him and I really hate that because then I feel really bad later. So once I notice something, I really try and bring it up right away, and you know, try and get past what I was feeling.”

Two of the siblings stated they “take their anger out” on either a family member or friend.

“I take out a lot of anger on my mom I think, which is bad. I yell a lot when there is nothing left for me to do, and I just start crying and yelling. I guess I just don’t know how to cope with it. So, I take it out on my mom, and she puts up with it. And sometimes, which I feel so bad about, I take it out on my sister by not wanting to be around her for a while. It is hard because I feel so bad when I take it out on her. That is the worst! I guess I also take out a lot of anger on my friends too. Maybe I need anger management! (laugh).”

All of the siblings reported that the most helpful coping strategy was, or would have been “expressing your emotions,” either by talking to someone, or writing down feelings.

“I think I probably would have (talked about it) if I knew what was best for me. I think it does help to talk about it because then you don’t bottle it up. If you bottle it up, you will explode... emotionally. You will totally explode, and it is going to stress you out even more than it should. You should get it out somehow. Either I write it down on a piece of paper, like in my journal, or talk to someone about it, like a counselor. It just helps to get it out.”

“It was helpful to talk about her illness. You don’t want to talk about it, but if you do, then you will feel better. You need to talk about it.”

Additional helpful strategies included using positive thinking (36%) and relying on religious beliefs and prayer (10%).

As a group, the siblings endorsed “positive thinking” as a primary way of coping with the early phases of treatment. This is in contrast to the individual interviews, where the majority of siblings stated they used distraction to cope with their feelings during their sibling’s treatment. Regarding current means of coping, nearly all of the siblings in the group stated that they think positively about their sibling’s prognosis and future, as well as focus on the accomplishment of their sibling surviving cancer.

“When I am feeling down about things, I just sit back and watch my little brother. I mean, I know the doctors said he wouldn’t live, but when you look at him, and you watch his smile, there is so much life there! And, there is so much hope in a 10 year-old boy. I mean, he conquered this! He can conquer the world if he wanted to. He gets picked on and you just get so defensive. He is the biggest brat, and he is so good at it! But, he also has so much life...So, watching him grow because he wasn’t supposed to...”

In addition, two of the siblings in the group stated that they still try and distract themselves when they are worried about a situation in their lives. The group endorsed “expressing emotions” and “positive thinking” as the most helpful coping strategies.

Parents reported that the siblings used a wide variety of coping strategies during the patient’s illness. These strategies included thinking positive (50%), using distraction (30%), isolating themselves (30%), talking about feelings to a family member (30%), engaging in an activity to directly help the patient (30%), and relying on their religion or faith (30%). Current coping strategies used by siblings as reported by parents included expressing their emotions (60%), thinking positive (40%), taking medicine for somatic complaints (30%), exercising (20%), and seeking information (20%). The coping

strategies the parents perceived as being helpful (or would have been helpful) to the siblings included expressing their emotions (60%), relying on faith (50%), thinking positive (40%), and seeking information (40%).

“(It was helpful for him) to talk. I think the worst thing siblings can do is to keep it inside, and not vent or be able to cry about it. Not to be able to ask questions. Having someone to talk to, and to get to them early, so they can get their questions answered.”

“He found a lot of peace through God and prayer. His faith was his biggest help. He was actually saying to me to go back to my prayers when I was having a hard time.”

“Getting the correct information was the best way for her to cope. Knowledge helped her. Knowledge is power. I used to sneak her (patient) file and do research to find out what all was going on. I think that is where she (sibling) got it.”

One parent talked about how focusing on a positive activity that would directly help the patient, as well as other children with cancer, was a tremendous help to the sibling.

“He kept asking me how we can save her...and then said, ‘I know I can help.’ His focus changed at that point. He wanted to do his Eagle Scout Project to raise money for kids with cancer. I told him it was a great idea, but that I was sorta tied up at that point and couldn’t help him with it. It was about 500 hours of service. I mean, how could I handle a major project like that! Something told me he would find a way. He spent 7 months planning a walk-a-thon that raised \$17,000. The only other time he cried was when Laura (patient) walked one lap at his project. It was so emotional...she was back in the hospital by 2:00. So, his drive changed...he really poured into this. It kept him SO focused.”

Helpful Interventions

The siblings were also asked to discuss interventions or strategies that helped, or would have helped, them cope with their sibling’s illness and treatment. The areas that the siblings gave the most attention to were needing to receive sufficient information about their sibling’s illness and treatment (91%), and receiving support from other siblings going through similar experiences (91%).

“I think (what would have helped) if I was more aware of what was going on. What was happening. Because, all I really knew was that she was going through chemo, and the cancer she had...and that she was bald, and that was pretty much it. I didn’t even know what the chemo was doing. Like, when she first got cancer, she did something that really scared us. We were all sitting in the living room and she comes out and starts dancing around and pulling her hair out everywhere. I was crying and told my mom to tell her to stop! I had NO idea what was going on. I mean, I knew she would go bald, but I didn’t know it would happen just like that!”

“I don’t believe it is right for parents to shelter their other kids. Not at all. If they are sheltering them, they have no idea what is wrong. They don’t know how far it can go...so, they don’t know how much they should worry and how much they shouldn’t. So, that is more stress on them if they don’t know.”

“Yes, definitely (would have been helpful to talk to other siblings who were going through the same thing)...because then you know that you are not the only one out there. And they know...they have experience and they know exactly what you are talking about. They are not going to just pity you. The last thing you want is pity. The last thing...especially when you can tell they don’t mean it. It helps so much to talk to people with first-hand experience.”

It is important to mention that, although only one sibling had the opportunity to attend a semi-structured group for patients and family members during the early phases of treatment, nearly all of the siblings discussed how having a sibling support group during that time would have been extremely beneficial.

Other helpful interventions and strategies included relying on their church for support (55%), how having someone to confide in (45%), and receiving more attention from their parents (27%).

“The church was really good to our family. Before every surgery and for the first month she was in the hospital, they made us meals...every single night we had meals. They had missionaries there and they were a blessing. It was cool, because when we were asking, ‘why, God, why,’ they would be there to talk to us. It was helpful to know that she would get a blessing before she went in for surgery...that she would be ok.”

“Well, one thing that I can say to siblings going through this is to find someone that you can talk to...because it is so important to talk about your feelings. If you don’t talk about your feelings, you are just going to feel miserable. And that is one

thing that bothered me the most...not being able to express myself. There were some days when I felt like I could not tell anyone how I felt...even my parents. I just didn't want to tell them. I was afraid that maybe I was being evil or something for having these thoughts. Siblings need to know that what they are feeling is not bad or anything. It is natural."

"I needed my parents more. I think I definitely needed them more. I think that if my parents would have spent more time with us, we would be a lot different now."

As a group, the siblings also discussed what was helpful to them, or would have been helpful, while their sibling was going through treatment. Similar to the individual interviews, the most common themes were receiving more information regarding their sibling's illness and treatment, needing attention and support from their family members, as well as opportunities to talk about their feelings, and wishing there were support groups designed for siblings of pediatric cancer patients. In addition, the siblings again discussed how *unhelpful* it was to hear about life expectancies from the medical team.

"I would tell siblings not to listen to that life expectancy thing. When my sister was diagnosed, she had like a 0% chance of making it through chemo because it was such a rare cancer. So, everyday through her chemotherapy, I would say, 'today is the day that she is not going to make it.' She made it through chemo, and then they said she wasn't going to make it to be a teenager...And she just turned 13 last week (tearful). I mean, I feel a little bit better because she conquered it, but up to that day, I was so scared to find out that her cancer would be back. That was one thing that stressed me out."

"Yea...the doctors told me Michael wouldn't live three months. He ended up living five more years."

Parent responses focused on increasing sibling support during the patient's treatment (80%), having correct and sufficient amounts of information (50%), receiving more attention from parents (30%), and seeking professional intervention (30%). Interestingly, three parents, after looking back to the early phases of treatment, now wished they would have pursued therapy for the siblings.

“Camp has been so important, because they cannot just discuss things like that with their friends at school. They have a special bond with camp friends because they can relate to one another. Their friends at school can listen, but it is not the same. They cannot really understand like someone who has gone through it...And, other than camp, there is nothing for siblings.”

“I think probably anything and everything that can be done with these kids (i.e., siblings) to educate them is the ideal situation. I think they need to get the correct information...to have as much of that available to them.”

“Holly (patient) went to a therapist, but none of the other kids did. That was a mistake. I should have taken them too. They needed it just before she lost her leg because they also had a sense of loss...and how to deal with her. It would have helped them to have someone to talk to, other than a parent, to express their feelings.”

“Parents dealing with a child with cancer become so focused on that child that they lose sight. Siblings need to be understood and they don’t need to be isolated! That is what parents do, they leave the siblings home and they take off to the hospital. When they come home, they say this is what is going on...but, they (i.e., siblings) have no choice, they have no say. Like they are not worth telling. They are not really allowed to have much of an opinion. And they are not really heard until it gets so bad that they start to act up or they become depressed that it becomes a necessity to deal with them. And then, they are looked at as a nuisance because they are taking the focus away from the child who needs it most. That is wrong.”

Summary of Research Question Five

The most helpful coping strategies according to both the siblings and the parents were expressing emotions, either by talking to someone or writing down feelings, using positive thinking, and relying on prayer. In terms of interventions, both the siblings and parents felt that receiving sufficient amounts of illness and treatment related information, as well as sibling support, in the form of support groups or sibling camp opportunities, would be the two most helpful interventions during the early phases of treatment.

Additionally, seeking professional intervention, receiving help from church members, and increasing parental attention to the sibling were also interventions the siblings and parents felt would be helpful to the siblings during the treatment phases.

Research Question Six

What do siblings report are the positive changes that resulted from their cancer experience?

Table 10 summarizes data from siblings and parents with regard to positive changes that occurred as a result of the cancer experience. Data include positive sibling effects, as well as positive family effects.

Positive Sibling Changes

Ninety-one percent of the siblings discussed how they feel they have “matured,” or broadened their character, as a result of the cancer experience.

“I matured a lot since then. I am more independent. I think (school is a big priority) because I matured a lot and realized, hey, this is my life and where I am going. I need to get my priorities straight.”

“Yes it made me upset, but I think it has bettered me. I have learned to do a lot better effort-wise in whatever I do...like 110%. It also made me think about the way I leave people. I want to leave them smiling, so if I never see them again, they will have a good memory of me.”

Additionally, 82% of the siblings talked about how they have a greater appreciation for life.

“I learned to appreciate life more...and not just with him, but other kids too. It just makes you look at how you are living your life.”

“I have a new outlook on life...anything can happen. It can change like that. So, whatever you need to do, you better do it, because you don't know what will happen tomorrow.”

Finally, 36% of the siblings reported that they feel they gained a great deal of information and illness-related knowledge from the cancer experience, and 27% stated that became more empathic and accepting of others.

Table 10

Percentages of Siblings and Parents Who Endorsed Positive Changes Due to Cancer Experience

<i>Category</i>	<i>Percentage</i>		<i>Response</i>
	<i>Sibling</i>	<i>Parent</i>	<i>Group</i>
Positive Changes for Sibling			
- More mature	91	60	P
- Greater appreciation for life	82	60	S
- More knowledgeable	36		
- More empathic/accepting of others	27	60	P
Positive Changes for Family			
- Family became closer	82	90	

S = "Salient" - majority of group endorsed

P = "Present" - some (or half) of group endorsed

NP = "Not Present" - question was asked and group did NOT endorse

Blank = question not asked directly and/or was not addressed by group

“People are amazed at how much I know medically. I grew up with it. I knew what to look for when she wasn’t right.”

“I have become a lot more sympathetic for people. Actually, I know how it feels to have a sibling or somebody in your family with cancer. So, when I hear that someone has cancer, I want to talk to them about it. I even got my Eagle Scout award for helping to raise \$16,000 for cancer.”

Focus group discussions focused on gaining an appreciation for life and not taking things for granted. Additionally, almost half of the siblings in the group reported that they became more empathic towards and accepting of others, especially those with disabilities. Interestingly, only a quarter of the siblings in the group discussed how they felt they “matured” as a result of the cancer experience, compared with nearly all of the siblings in the individual interviews.

Similar to the individual and the group interviews, the parents reported that the siblings were more mature (60%), had a greater appreciation for life (60%), and were more empathic and willing to help and accept others (60%).

“I think she has a deeper understanding...a lot more mature for her age. She sees life in a more profound way than I think most kids her age. I think she realizes that life can be somewhat tentative, and you have to really value every moment with every friend you have. She feels that way, normally you don’t develop that until you are older.”

“She doesn’t look down on people in society, of any race, illness, or disability. She will go out of her way to help and take care of someone else. She will give of herself and be the first to help.”

“She is more sensitive to others, especially those with special needs. It is amazing, she has a deeper sense of justice and injustice, and makes sure that if there is an underdog, they are not being treated with cruelty. I am so proud of her.”

“There is so much joy that is not written about and so many positive things that I was not aware of. It has changed his life! I think he has matured beyond his years. He believes there is a purpose for everything and he learns from it.”

Positive Family Changes

Eighty-two percent of the siblings reported that their family became closer as a result of the cancer experience, while 18% stated their family closeness suffered.

“The way I see it, him having leukemia was the best thing that ever happened to our family. We pulled together, and it has been good for everyone in our family.”

“It actually made us closer. It made us talk more...express feelings. It made us bond because we were forced to be together so much.”

No family benefits were discussed in the group interview. Ninety percent of the parents stated that their families became closer as a result of the cancer experience, and how the siblings have a greater appreciation for their families.

“I think it has made him appreciate the family more. We are extremely proud and lucky. We have been so blessed. I see what some other families go through with their kids. Other people may have a lot more money than we do, but we have got good kids! That is what’s important.”

“It cemented our unity! It was hard for us at first, trying to put the family back together again and be normal. We needed to learn how to be a family that didn’t have crisis. But, no matter what mistakes we make, we know that trust and love will always be there. I think we have a really great family.”

Summary of Research Question Six

In summary, both the siblings and the parents saw many positive outcomes for the sibling and the family as a whole that resulted from the whole cancer experience. These positive changes include a deeper appreciation for life, increased maturity, a heightened sense of empathy, the willingness to help and accept others, and family closeness.

Additional Results

One of the benefits of choosing a qualitative methodology, and using interviews to collect data, was that it allowed the siblings to “tell their stories” and express their feelings both individually and in a group setting, which was a form of “support” for them. To

further demonstrate the effectiveness of offering the siblings an opportunity to discuss their feelings related to their cancer experiences, the researcher asked the participants to complete a short survey where they rated the program and provided comments (Appendix H). This component was not part of the original research methodology, but was added after the interviews took place. On Likert scales from 1 (unhelpful) to 5 (very helpful), the siblings rated the individual interviews an average of 4.82; the group interview, 4.73; and the overall project, 4.91. Comments made by the sibling included thoughts about their individual experiences.

“I have never talked about my situation. I didn’t know I had so much inside.”

“Someone cared enough to talk about my own story.”

“I can honestly say I got more out of it than I expected.”

Other comments included the siblings’ thoughts on the supportive nature of the group.

“I didn’t expect for others to feel the same way I did.”

“It allowed me know my comments helped others.”

“I wish they had more programs like this.”

“It was the bomb!”

Similarly, the parents offered unprompted comments about the study in their interviews after camp.

“I first have to say that the study you did at camp was so great. He said it was the best part about camp! He didn’t use the word ‘healing’ but I knew what he meant...It was just so therapeutic.”

“Your study made her feel so special. She did not stop talking about it all the way down the mountain!”

“He said afterwards that it really helped him to talk about his brother, and it also helped him to listen to what others were going through. It was kind of like a healing session for them.”

CHAPTER VI: DISCUSSION

Research Questions

This study examined siblings' and parents' perceptions of the pediatric cancer experience and its impact on siblings' long-term adjustment. A qualitative research design was selected due to limited knowledge about this topic. The researcher used two methods of data collection from the same informant (i.e., individual interviews and group interview with siblings), and two different informants (i.e., siblings and parents). Findings that were found across participants, data collection methods, or informants were considered more valid than findings that were only found in a limited number of participants, or in one interview format. In several instances, parental perceptions differed from siblings', despite strong consistency across sibling participants and interview format. In cases where these differences in perception concerned the feelings and views of the siblings themselves, the views of the siblings were treated as valid. Possible reasons for the lack of consistency between siblings and parents are discussed, as well as the implications for this research and future research.

Research Question One: Information Presented to Sibling at Time of Diagnosis

Over half of the siblings in the current study felt that due to either their age at the time of diagnosis, their parents' fears of upsetting them, or their parents' lack of information, they were not given sufficient amounts of illness-related information. Additionally, nearly all of the siblings felt that receiving appropriate and sufficient information about the patient's illness and treatment was (or would have been) one of the most helpful interventions to aid in their overall adjustment. Siblings' desire to receive more information pertaining to the patient's diagnosis, treatment, and related side effects

has been documented in the literature in studies assessing sibling adjustment to cancer (Koch-Hattem, 1986; Kramer, 1984; Martinson et al., 1990). According to Martinson et al. (1990), age-appropriate information presented to the siblings at the time of diagnosis, as well as throughout the patient's illness, is crucial in order to prevent the "dramatic fantasizing" that may occur when children are faced with unknown situations. A related topic is the issue of sibling participation throughout the patient's treatment. In the current study, nearly all of the siblings (individually and in the group) and parents felt that ongoing involvement of the siblings in the patient's care was essential to overall sibling adjustment. It has been suggested that encouraging siblings to visit the hospital and be involved with the patient's care could help to increase their knowledge and understanding about the treatment and, therefore, reduce their fear (Chelser et al., 1991; Evans, 1992; Kramer, 1984; Matinson et al., 1990). In fact, some pediatric hospital programs have responded to the need of providing siblings with illness and treatment-related information by creating hospital and clinic "visiting" days where siblings can become acquainted with the setting, instruments, procedures, and staff that the patient has been involved with during treatment (Martinson at al., 1990).

Although siblings in the current study conveyed a desire to receive illness and treatment-related information, they also expressed strong feelings against receiving "percentages" from physicians related to the patient's overall prognosis, which may appear contradictory to the current findings. It is important to note that the majority of these siblings have brothers and sisters who survived cancer. Therefore, these siblings had received warnings that, although accurate at the time of diagnosis and treatment, turned out to be untrue, and caused them a great deal of anxiety. It is possible that the

siblings would have felt differently about receiving prognosis statistics if the patient had died. For patients who do not “beat the odds,” research suggests that siblings’ adjustment to the death of a brother or sister is greatly influenced by the degree of involvement the sibling has with the patient and his or her treatment (Adams-Greenly, 1984; Balk, 1983b; Davies, 1988; Hogan & Balk, 1990; Lauer et al., 1985). Specifically, these authors found that the more involved the siblings were during the patient’s treatment, the more prepared the siblings were for end of life issues and subsequent bereavement. Therefore, conveying prognosis information to family members, which may create initial anxiety, may also be necessary to prepare the family to have realistic survival expectations.

Research Question Two: Most Significant Concerns at Time of Diagnosis

The majority of siblings, both individually and in the group, reported their primary concern at the time of diagnosis was the patient’s survival. Other concerns included worrying about emotional and financial stability of the family, contagion of the illness, and the patient’s daily functioning. These concerns have been widely represented in the literature, especially in qualitative studies of sibling adjustment to cancer (Bendor, 1990; Chelser et al., 1991; Menke, 1987; Koch, 1985; Koch-Hattam, 1986; Kramer, 1984; Sourkes, 1980; Walker, 1988). For example, Haversman and Eiser (1994) reported over half of the siblings in their sample stated the patient’s survival was their primary concern also.

Given that cancer is a life-threatening disease, the finding that survival is the primary concern for siblings is not surprising. The other concerns mentioned by siblings are consistent with an understanding of the diagnosis and its potential impact on the sibling and family. Although these findings are consistent with the research literature, it

is also likely that siblings' memories about their initial concerns may have been colored by their current understanding of cancer and its impact on the child and family members. For example, concerns about loss of parental attention have been mentioned as a concern for siblings at the time of diagnosis (Chesler et al., 1991). However, no siblings and only one parent mentioned this as an issue in the present study.

Research Question Three: Salient Aspects of Cancer Experience

Both the majority of the siblings and the parents in the current study felt the most difficult aspect of the cancer experience was the uncertainty of the patient's prognosis. Other salient aspects included changes in family life (e.g., increased stress, change in responsibilities), and for the siblings, social relationships (e.g., spent less time with peers). Changes in family functioning (e.g., cohesion, expressiveness, role/responsibility changes), and subsequent effects on overall sibling adjustment have been discussed at length in the sibling oncology literature (Brett & Davies, 1988; Iles, 1979; Kazak & Meadows, 1989; Sahler & Carpenter, 1987; Sawyer et al., 1986). Changes in the sibling's peer relationships have also been reported in the literature (Brett & Davies, 1988; Hogan, 1988; Hogan & Balk, 1990; Walker, 1988); however, primary themes typically center around tension in the peer relationships, rather than spending less time with their peers due to treatment responsibilities. Only 36% of the siblings in the current study reported strained interpersonal relationships, whereas the majority of siblings reported spending less time with peers.

Neither the siblings nor the parents in the current study reported changes in the sibling's academic functioning (i.e., increase in absences, poor grades) during the initial phases of treatment. Although it is reasonable to expect that academic problems occur

for siblings due to excessive absences, difficulty concentrating, or decreased parental supervision with homework, there is very limited evidence in the literature for this finding. What does exist is evidence for academic difficulties in siblings of other chronic illnesses such as spina bifida (Tew & Laurence, 1973) and renal disease (Vance, 1980), or in siblings of pediatric cancer patients who died from their illness (Balk, 1983a; Davies, 1993; Kaplan, 1976). For siblings of children who survived cancer, one study reported difficulty completing homework in 60% of the sample (as reported by parents), but only 17% of the sample (as reported by siblings). In the current study, although only a small number of siblings reported an increase in absences or a decrease in grades, several of them reported that they felt their teachers were more “lenient” on them due to their situation at home, or that it was very difficult to attend school, especially when they were worried about the patient.

The majority of siblings in the individual and group interviews admitted to feelings of jealousy and anger related to the various changes that took place in the sibling’s life as a result of the illness. Anger, jealousy, and overall irritability are well represented in the sibling literature during the initial phases of treatment. (Barbarin et al., 1995; Carpenter & Sahler, 1991; Havermans & Eiser, 1994; Iles, 1979; Koch, 1985; Koch-Hattem, 1986; Kramer, 1984; Lavigne & Ryan, 1979; Martinson et al., 1990; Schuler et al., 1985). The fact that the siblings in the current study still report these feelings as being salient in the initial phases of treatment further supports the significance of these findings. One aspect that is frequently reported in the literature, but was not a finding in the current study, is somatization (Bendor, 1990; Carpenter & Sahler, 1991; Koch, 1985; Walker, 1988) and fears of own death (Lavigne, 1980) in the healthy sibling.

Although one participant in the study reported vomiting when anxious, no other siblings or parents in the current study reported the sibling exhibiting somatic complaints or worrying about their own health at the time of diagnosis or treatment.

Research Question Four: Current Concerns and Functioning

Concerns about the patient's possibility of relapse and ability to function independently in society (with regard to cognitive and learning difficulties, fertility issues, and growth deficiencies) were reported by the majority of siblings and nearly half of the parents in the current study. However, the sibling oncology literature offers only "anecdotal" evidence that siblings continue to worry about these issues years after treatment has subsided (Kramer, 1984). The lack of evidence in the literature may be due to limited studies on long-term effects in siblings of pediatric cancer patients. However, it is also possible that these residual concerns arise from the fact that many of these siblings continue to have contact with oncology families after treatment (e.g., camp), and therefore, learn about relapses, deaths, and overall functioning difficulties from other families. Nonetheless, worrying about relapse is understandable given the relapse rates between 10 and 50 percent, depending on the type of cancer and length of remission (Gold, 1999). Therefore, helping siblings cope with these fears may be a good focus for intervention efforts.

In terms of individual relationships, nearly all of the siblings and parents reported that they (sibling and parent) have a closer relationship since the illness. The siblings and parents also reported that the sibling maintains a close relationship with the patient, although over half of the siblings and parents state that the sibling continues to feel "responsible" for and "protective" over the patient, even years after treatment has ended.

Although increased family cohesion has been reported in studies of short-term effects of pediatric cancer (Chesler et al., 1991; Sargent et al., 1995), there are no methodologically sound long-term studies that have addressed this area. Despite the fact that both siblings and parents in the present study perceived they had a closer relationship as a result of cancer, it is possible that their perceptions may be colored by efforts to see a positive side to a stressful experience. One direction for future research would be the examination of parent/child relationships and family characteristics in families that have experienced cancer and similar families without this experience, using objective measures of parent/child relationships and family cohesion.

There is also no mention of siblings continuing to feel responsible for or protective toward the patient in studies examining long-term effects of cancer on siblings, however the chronic illness literature offers some insight in this area. Specifically, Menke (1987) evaluated 72 siblings of children with chronic illnesses (i.e., cancer, cystic fibrosis, lung-heart disease, spina bifida, and severe burns) and found that 49% of the siblings reported “protective” concerns over their sibling, with the majority of them being older than the chronically ill sibling. In the current study, six out of ten participants reported feeling protective over the patient, with four of these siblings being older than the patient.

Regarding the siblings’ reports of affect years after treatment has ended, nearly two-thirds of the siblings in the individual interviews, and the majority of siblings in the group interview, admitted to residual feelings of guilt. Specifically, the siblings stated that they currently felt guilty about either leaving the patient (e.g., to go away to college), the way they sought attention from their parents when their brother or sister was diagnosed, how they treated their sibling during the illness, and/or in their interactions with other siblings

who have lost a brother or sister to cancer. This finding is important considering the lack of evidence in the literature related to long-term effects of cancer on siblings. Findings that do exist in this area do not identify feelings of guilt as a major issue for siblings, however, as described earlier, there are many methodological concerns associated with this body of research. What the literature does present is partial evidence for residual feelings of jealousy and anger related to continued differential treatment of the child who had cancer (Kramer, 1984; Peck, 1979). It is possible that addressing siblings' emotions surrounding their brother or sister's cancer in the initial phases of treatment would alleviate feelings of guilt that often persist years after treatment has ended. Evaluating long-term adjustment in siblings who did receive either professional intervention or support group services where feelings were addressed, compared to siblings who did not receive such interventions, would be one way to evaluate intervention efficacy.

Research Question Five: Helpful Coping Strategies and Interventions

The current study examined the siblings' and parents' views on the most helpful and useful intervention strategies that were (or would have been) valuable to the siblings' overall adjustment during their cancer experience. Siblings and parents of cancer survivors viewed two things as important to siblings' overall adjustment: (a) receiving sufficient information about the patient's illness and treatment, and (b) finding appropriate ways to express concerns and feelings regarding the various changes that take place when the patient is diagnosed, either through professional intervention or support groups designed for siblings.

In the current study, all of the siblings and over half of the parents stated that expressing feelings was the most helpful coping strategy, which is interesting considering

that only one third of the siblings reported actually using this strategy during their sibling's illness. As reported earlier, many of the siblings felt like they could not express their feelings to their parents for fear of causing additional stress, thus choosing instead to hold their feelings inside. Furthermore, given the fact that only one sibling reported receiving professional counseling, and only one other sibling being involved in a support group, it is likely that the siblings felt they had limited options and opportunities to vent their feelings. Expressing feelings as a way to cope with all the changes brought about by having a brother or sister being treated for cancer is noted in the literature (Chesler et al., 1991; Kock-Hattam, 1986; Walker, 1988), however, most of these studies did not assess how helpful this strategy was to the siblings. Understanding what coping strategies siblings feel were (or would have been) helpful to their adjustment is beneficial in designing interventions to assist siblings with adjusting to the demands of cancer in their families. However, controlled studies are needed to examine whether what siblings perceive as helpful actually has an impact on sibling short-term and long-term adjustment.

Other than individual counseling, siblings can also receive a great deal of support through the avenue of support groups, which can be offered through the treating hospital, special camp sessions devoted to siblings, or organizations focused on providing support for family members of cancer patients (e.g., Candlelighters). Although participation in support groups is often difficult to accomplish due to logistical concerns (i.e., living a large distance from the treating facility), nearly all of the siblings and parents in the current study reported that being involved in a support group, either through the hospital or camp, was (or would have been) one of the most helpful interventions in their

adjustment to the cancer experience. The value of support groups designed for siblings of pediatric cancer patients has been reviewed in the literature, and found to be extremely effective in helping siblings cope the family changes and emotions associated with living with a brother or sister with cancer (Carpenter, Sahler, & Davies, 1990; Cunningham, Betsa, & Gross, 1981; Sahler & Carpenter, 1989). For example, Adams-Greenly and colleagues (1986) designed a one day, intervention program called SIBS (Specially Important Brothers and Sisters), which provided education, encouraged the expression of difficult feelings, and fostered adaptive coping. The workshop is divided into three segments which includes (a) education, where the siblings are led in a discussion about cancer by physicians and oncology nurses, and then taken on a tour of the clinic and hospital where all procedures are demonstrated; (b) support, where siblings watch a video of other siblings and then are led in a discussion with the social worker that focuses feelings and coping; and (c) recreation, where siblings interact with each other during games and group activities. When evaluating the program, 87% of the siblings who attended the workshop reported that they felt the program was very helpful to their overall adjustment. Specifically, these siblings rated the hospital tour, videotape, and “doing the needles” as the activities they liked the most, followed by meeting other siblings like themselves, being able to discuss their feelings, and learning more about cancer. Through questionnaires that the siblings completed at the end of the session, the authors were able to determine that the program benefited the siblings by educating them about cancer, allowing them opportunities to verbalize their feelings, identify with other siblings in the same situation, and find effective methods to cope with problems arising from the cancer experience. In addition, according to parent evaluations, 90% of the siblings had an

increase in knowledge about the patient's illness, 70% felt the siblings were more comfortable with the hospital environment, 65% felt the sibling felt more comfortable talking about the illness with the parent, 60% of the siblings learned and were using more effective coping strategies, and 58% reported the sibling became less angry or resentful.

The efficacy of similar intervention programs with siblings of pediatric cancer patients has been demonstrated in the literature. For example, Houtzager and Grootenhuis (2001) evaluated anxiety in 24 siblings of pediatric cancer patients before and after a five week intervention group that focused on effective coping strategies, and found a significant decrease in overall anxiety on the *State-Trait Anxiety Inventory* at the end of the group intervention. However, as noted earlier, the benefits of these interventions have not been examined in control group or treatment comparison group designs.

Research Question Six: Positive Changes

The same experiences that threaten siblings' adjustment can also produce growth. Positive effects from the cancer experience, both for the sibling and for the family as a whole, were described by the siblings and the parents. Specifically, the majority of siblings and parents described how the whole cancer experience has increased the siblings overall maturity, increased their knowledge base, taught them to be more empathic and accepting of others, and given them a greater appreciation of life. Regarding family benefits, the majority of siblings and parents report that, as a whole, the family became closer as a result of the cancer experience. Individual and family positive effects have been frequently noted in the literature (Barbarin et al., 1995; Chesler et al., 1991; Evans, 1991; Davies, 1995; Havermans & Eiser, 1994; Sargent et al., 1995).

General Discussion

Across individual and group formats, and sibling and parent interviews, a complex view of sibling long-term adjustment emerges. Years after treatment, a sibling's and family's experience with cancer continues to be a salient event for the well sibling. In addition to expressing strong feelings about how their individual and family lives changed as a result of the cancer experience, siblings also report continued fears for the now healthy patient, both with the potential for relapse, as well as their ability to function independently in society. Closely tied to these concerns are their residual feelings of guilt, due to either seeking attention from their parents while the patient was enduring painful treatment (especially if the patient continues to have physical and/or cognitive impairments), or due to wanting to pursue their own goals and career plans, but feeling unable to relinquish the "adult role" they inherited during treatment and having the desire to continue protecting the patient. In addition, considering the fact that siblings report feeling uncomfortable expressing these emotions during treatment for fear of increasing stress in an already fragile family situation, years later, siblings may be left with lingering feelings that have never been addressed. They must now either find appropriate ways to express their feelings (either directly through professional intervention, or indirectly through creative means such as writing/art or camp opportunities), or risk future emotional difficulties.

The importance of focusing on long-term effects of cancer on siblings is being able to identify salient factors that could be addressed early in the treatment process. This study offers that knowledge, directly from the siblings themselves. The siblings in the current study described stories that were both emotional and enlightening. They provided

answers to questions that can directly affect intervention efforts geared toward coping with pediatric cancer. For example, interventions could include efforts to educate the sibling about the patient's diagnosis, treatment, and related side-effects, provide opportunities to talk about the various changes in their family and peer interactions, as well as the feelings associated with these changes, and to offer a variety of support services to exchange information with other siblings who are enduring, or have endured similar experiences. Based on the siblings' views, the expression of feelings and group support are critical aspects of interventions, although more research is needed that validates the efficacy of these strategies in helping siblings cope with the cancer experience.

One particular theme that was observed across many of the research questions in the study was the display of affect, both in the siblings expressions of feelings related to their sibling's illness, as well as in the manner in which their cancer experiences were expressed during the interviews. One example of affect in the current study (as reported by both siblings and parents) was the siblings' ongoing fear about the possibility of their sibling relapsing. Specifically, not only did the majority of siblings worry about their brother or sister's survival at the time of diagnosis, but even years after treatment has ended, over half of the siblings reported that they continue to worry about the possibility of relapse, as well as the patient's ability to function independently.

Second, jealousy and anger, related to the loss of attention when their brother or sister was diagnosed, were reported by the majority of siblings in the individual and group interviews. Feelings of residual guilt were described by nearly two-thirds of the siblings when discussing their current functioning.

Finally, regarding affect during the interviews, it is important to note the overall “emotionality” that was evident while the siblings told their stories in the current study. Specifically, two-thirds of the siblings in the individual interviews, and nearly all of the siblings in the group interview became tearful at least once while they were describing their cancer experiences. For example, some siblings became tearful when describing the treatment the patient went through, when explaining reasons for their guilt, and/or when thinking about the patient’s possible relapse and limitations.

Many parents may not recognize the adjustment difficulties siblings have when a child is diagnosed with cancer, which was another important finding in the study. For example, parents and siblings differed on several important points including the amount of illness-related information that was given to the sibling during the initial phases of treatment (i.e., siblings felt the information was not sufficient), the changes in the sibling’s responsibilities at home (i.e., siblings felt they had a significant increase in household chores and childcare), the amount of jealousy and anger the sibling felt surrounding the loss of attention (i.e., siblings endorsed high levels of jealousy/anger), and the amount of residual guilt the siblings experience even years after their sibling was treated for cancer (i.e., siblings endorsed considerable feelings of guilt currently).

According to the literature on parent-child agreement in data collection, some behaviors, especially internalizing behaviors, may not be as readily detected by parents (Achenbach et al., 1987; Breslau & Prabucki, 1987; Edelbrock et al., 1986; Menke, 1987; Walker, 1988). It is also possible that stressful life events, such as a cancer diagnosis in the family, may alter parental mood and perceptions, so that their interpretations of the child’s behavior are somewhat inaccurate (Cohen et al., 1994). Finally, it is also likely

that parents are not available to attend to the needs and feelings of siblings due to their own stress, as well as their own feelings of guilt associated with the patient's diagnosis and potential feelings of helplessness.

Limitations

There are several limitations to this study. The use of a small sample size may limit generalizability of the findings. Although most advocates of qualitative methodology argue that this limitation is more than compensated for by the depth of analysis (Chesler et al., 1991; Kidd, 2002; Koch, 1985), it would be worthwhile to measure responses from a larger, more diverse population of siblings (e.g., with respect to age, gender, ethnicity, sibling position, diagnosis, etc.). In addition, results may not be generalizable to siblings of patients who died as a result of their illness. As discussed earlier, it is likely that siblings will experience difficulties related specifically to bereavement issues. Findings may also not be generalizable to siblings and families who chose not to attend the camp session. Siblings and families who choose to attend camp may be more amenable to group-oriented, support services in general, thus potentially inflating the present finding of the value of seeking help through such venues. Some families may find other support services (e.g., individual counseling/family/church) more helpful to their particular situations.

Another limitation of the study involves relying on siblings' memory of events. Although assuming that memories of traumatic events are more accurate than less stressful events (Koch, 1985), which may lessen this concern, it is important to recognize that after a delay in time, it is not uncommon for individuals to unconsciously distort their interpretations of events, or exaggerate or minimize the significance they attach to these

events (Sattler, 1998). Therefore, it is important to note that the current study was not an attempt to describe what actually occurred to siblings during their sibling's illness, but to understand the significance the siblings presently attached to this traumatic time in their lives.

The last limitation in the study was the inclusion of one sibling of a deceased child in the sample of interviewed siblings. Although responses pertaining to time of diagnosis and initial treatment are similar for siblings of surviving and deceased children, some adjustment differences have been found. For example, Martinson and his colleagues (1990) found siblings of deceased children expressed more fears about their own health, fears of losing additional family members, and tended to avoid certain words (e.g., "cancer") when discussing their sibling's illness. Although the intent was to include only siblings of surviving cancer patients in the current study, the researcher felt that when it was realized that one participant had a deceased sibling, it was unethical to remove him from the group. Therefore, it is possible that the addition of this sibling in the focus group may have changed what group members were willing to discuss. Given the similarities between the group and individual interview responses, however, this appears unlikely. Furthermore, adding this particular sibling could have prompted the discussion of "survival guilt," which was an important finding.

Future Directions and Practical Implications

Despite the limitations presented, the results of the current study provide a rich foundation from which to build a better understanding of siblings' adjustment to pediatric cancer, however many questions remain unanswered. Particularly important are the processes that contribute to adjustment difficulties as well as the protective factors that

are associated with healthy adjustment. Patterson's model (Patterson et al., 1992), described earlier, is a prime example of how parenting practices (i.e., "protective factors") and contextual factors (i.e., "risk factors") can affect a child's adjustment. When adapted and extended to explain sibling adjustment to pediatric cancer, it may then be possible to assess how parenting practices (e.g., monitoring/involvement, discipline strategies, parental coping, and family communication) can mediate the relationship between contextual factors (e.g., stress of the cancer diagnosis, pre-existing family psychopathology, strain on marital relationship, financial stressors, and lack of parental social support) and individual sibling factors (e.g., developmental stage, their perceived threat of the illness, existing coping skills, pre-diagnosis psychosocial functioning) in the overall prediction of sibling adjustment. Since the in-depth information obtained from the siblings themselves illustrated many of these family and contextual factors (i.e., lack of parental availability/monitoring, differential discipline techniques, coping strategies, family communication), further research is needed to better understand exactly which factors predict successful and unsuccessful sibling adjustment to pediatric cancer within a family theoretical model.

It is important that future research build upon the findings of the present study, following up on the areas of difficulty identified by siblings and investigating the efficacy of the coping strategies identified as helpful by the siblings themselves. Large scale studies of sibling adjustment are needed, as well as longitudinal studies. For example, future research might involve interviewing the siblings over several years, from the time of diagnosis to years after treatment has ended. This strategy would allow the researcher to determine if the factors that were salient at the time of diagnosis are the same factors

that are salient during treatment and years after treatment as ended. In addition, using a longitudinal design would allow for a more thorough assessment of ongoing family adjustment and coping. Future research could also focus on understanding the long-term effects of sibling adjustment to specific types of pediatric malignancies (e.g., brain tumors, leukemia, orthopedic cancers, etc.). It is likely that malignancies that often result in significant physical and/or cognitive impairment may cause additional stress for the healthy sibling long-term.

The present study provides many ideas for designing helpful interventions for siblings of pediatric cancer patients. However, it cannot be assumed that simply because interventions incorporate suggestions from siblings themselves that the interventions are effective. There is a need for controlled studies of sibling interventions and their impact on siblings short- and long-term adjustment. For example, siblings reported that providing detailed information on treatment would have been beneficial in their efforts to cope with their sibling's illness. The importance of this element in sibling programs could be tested by randomly assigning siblings to programs that give more and less detailed information about the siblings' illness and treatment (e.g., video, book) and comparing siblings' reported levels of distress in the two programs.

Implications for School Psychologists

Nursing, social work, and psychology literature provide a multitude of helpful suggestions in facilitative coping in siblings of a pediatric cancer patient, however, most of these recommendations center around hospital or clinic based treatment. Fortunately, some recommendations can be utilized for school based interventions as well (Bendor, 1990; Koch-Hattem, 1986; Kramer, 1984; Walker, 1990). School psychologists, when

confronted with issues surrounding a sibling adjusting to pediatric cancer, may be in a good position to not only help the sibling cope with their feelings about the illness and treatment directly, but can also educate teachers and other school staff about the various psychosocial issues that often result from the family cancer experience. This can be especially important in families where parents are often unavailable to attend to the needs of the siblings at home or in school due to the demands of the patient's treatment. For example, school psychologists can encourage teachers to make appropriate accommodations for completing late assignments due to hospital visits and/or family responsibilities, give the sibling some "favored" responsibility in the classroom to help the sibling feel "important," and reassure the sibling that arrangements can be made to call the hospital during the day if needed when the patient is admitted for treatment. Lastly, school psychologists can make frequent contact with the sibling's teacher to consult on observations related to the sibling's emotional or behavioral functioning in the classroom.

School psychologists can also be a good resource for parents and/or extended family members of siblings coping with pediatric cancer. They can help educate caretakers about sibling adjustment issues, such as the natural tendency to take on an "adult role" at home, feeling the need to seek attention from caregivers, and the dangers of internalizing feelings for fear of causing additional stress in the family. They can also stress to the caregivers the sibling's need for ongoing information throughout the patient's treatment, as well as opportunities to participate in the patient's care (e.g., calling/visiting the patient, making a card to send to them). Caregivers should also be

encouraged to continue sibling involvement in activities (e.g., sports, clubs) in order to maintain peer interaction and normalcy.

Most importantly, findings from the current study suggest that siblings need someone to talk to. School psychologists can either provide individual counseling to the sibling to facilitate healthy coping, or make a referral to an outside professional if warranted. Additionally, encouraging the sibling to use his/her cancer experience in writing or art assignments may help the sibling express feelings and/or help communicate illness-related information to peers. Siblings should also be encouraged to maintain focus on their own goals (athletics/school/career plans), and school psychologists can help them make steps to reach these goals. Finally, participation in a support group with other siblings of medically challenged children may be beneficial for overall adjustment.

Conclusion

It is likely that no one study is able to provide definitive answers to the questions raised about how siblings cope with the cancer experience, and what factors predict successful adjustment over the course of treatment. What this study may contribute, however, is another piece to the puzzle in the understanding and awareness of siblings' adjustment to pediatric cancer. The descriptive methodology used in the current study afforded the siblings the opportunity to educate health care professionals in what it is really like to live with a sibling with cancer, and how that experience affects their lives. When viewed collectively, each aspect of the illness represents an emotionally overwhelming and stressful time for the sibling, even years after treatment has ended. They were subjected to a tremendous amount of change in their lives, and they had to cope with these changes in the face of much uncertainty and, often times, limited

emotional support. Although it is not feasible to assume that the stressors siblings face can be entirely prevented, it is realistic to expect that by either providing individual counseling, offering opportunities to participate in support groups, or making appropriate referrals near the sibling's home, these stressors can be addressed and effectively managed upfront, before they have the opportunity to intensify during the course of treatment and years later.

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APPENDIXES

Appendix A

Time Line Exercise

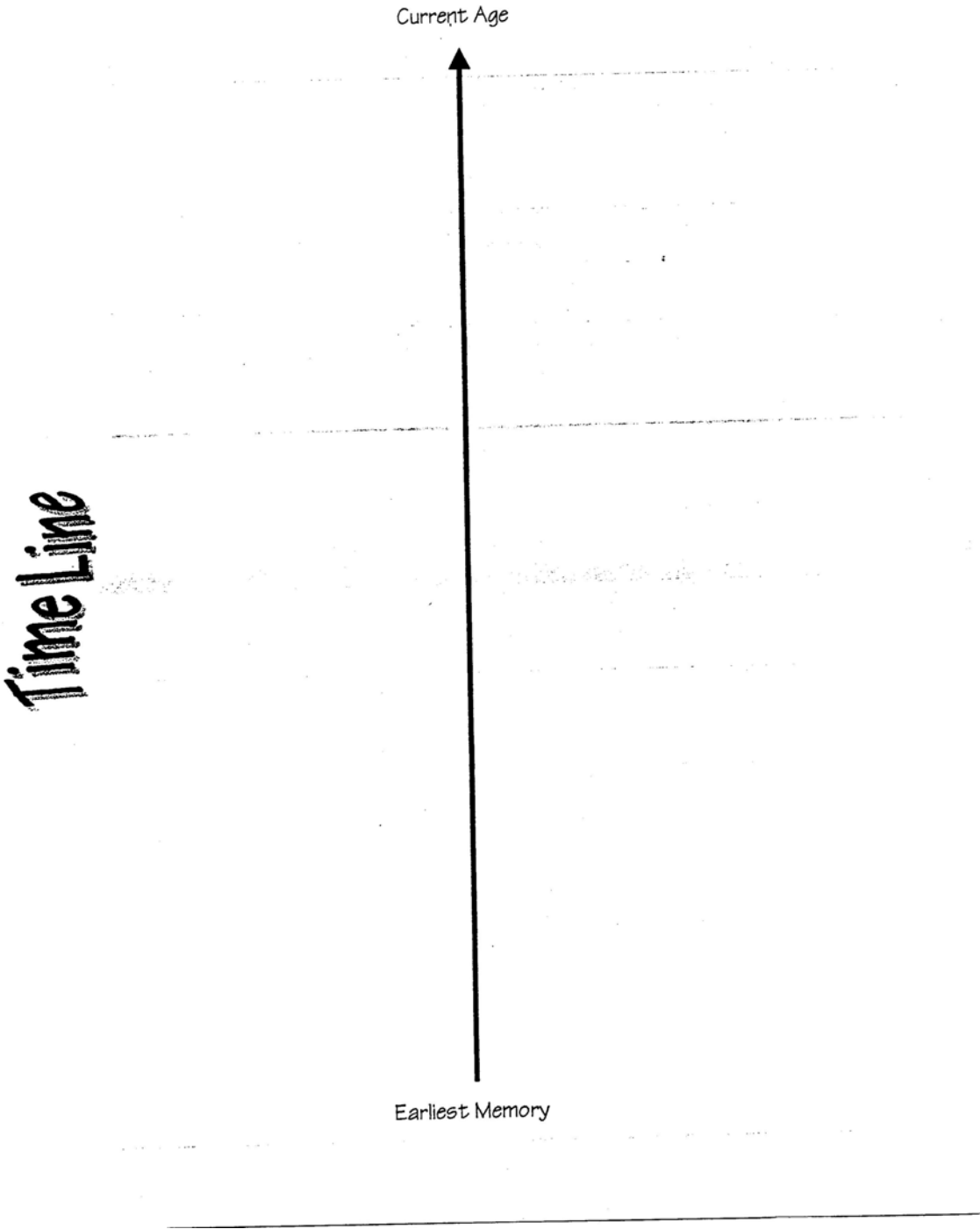
AS YOU KNOW, THE PURPOSE OF THIS STUDY IS TO GAIN AN UNDERSTANDING OF HOW IT FEELS TO HAVE A BROTHER OR SISTER WHO HAS RECEIVED TREATMENT FOR CANCER. I WILL BE ASKING YOU SOME QUESTIONS ABOUT WHAT THINGS WERE LIKE FOR YOU AT THE TIME YOUR BROTHER/SISTER WAS DIAGNOSED, AS WELL AS HOW THINGS ARE FOR YOU NOW THAT THEIR CANCER HAS BEEN TREATED. IN ORDER TO HELP YOU THINK BACK TO WHEN THESE EVENTS OCCURRED, I HAVE A TIME LINE EXERCISE FOR YOU TO COMPLETE THAT WILL HELP YOU REMEMBER SPECIFIC TIMES, PLACES, AND PEOPLE THAT SURROUND THE EVENTS YOU WILL POINT OUT. (*Present the time line to the sibling*).

THIS IS A “TIME LINE.” IT BEGINS WITH THE FIRST THING YOU CAN REMEMBER WHEN YOU WERE A YOUNG CHILD, AND ENDS WITH THE PRESENT (I.E., YOUR CURRENT AGE). WHAT I WOULD LIKE FOR YOU TO DO IS THINK ABOUT ALL THE EVENTS THAT HAVE HAPPENED IN YOUR LIFE THAT YOU CONSIDER “MEMORABLE,” WHETHER THEY BRING BACK POSITIVE FEELINGS, NEGATIVE FEELINGS, OR NEUTRAL FEELINGS. AS YOU CAN SEE, THE TIME LINE IS DRAWN IN THE MIDDLE OF THE PAGE AND HAS ROOM FOR YOU TO PLOT OUT SEVERAL IMPORTANT EVENTS EITHER ABOVE THE LINE, IF YOU CONSIDER THEM POSITIVE, BELOW THE LINE, IF YOU CONSIDER THEM NEGATIVE, OR SOMEWHERE IN BETWEEN.

EVEN THOUGH WE ARE FOCUSING PRIMARILY ON WHAT THINGS WERE LIKE FOR YOU DURING YOUR BROTHER’S/SISTER’S ILLNESS, I AM ALSO VERY INTERESTED IN OTHER EVENTS IN YOUR LIFE THAT YOU CONSIDER TO BE IMPORTANT. THIS WILL ALLOW ME TO SEE HOW THESE OTHER EVENTS COMPARE TO EVENTS THAT SURROUND YOUR SIBLING’S ILLNESS.

WHERE I WOULD LIKE FOR YOU TO BEGIN IS RIGHT HERE WITH THE EARLIEST THING YOU CAN REMEMBER. TRY AND THINK ABOUT HOW OLD

YOU WERE AT THIS TIME, WHERE THIS EVENT TOOK PLACE, WHO WAS INVOLVED, AND IF THIS MEMORY WAS POSITIVE, NEGATIVE, OR SOMEWHERE IN BETWEEN. THEN I WILL GIVE YOU SOME TIME TO PLOT OUT OTHER EVENTS IN YOUR LIFE THAT ARE IMPORTANT TO YOU. PLEASE INCLUDE THE TIME WHEN YOUR BROTHER/SISTER WAS DIAGNOSED WITH CANCER, AS WELL AS ANY SIGNIFICANT EVENTS THAT TOOK PLACE IN YOUR LIFE DURING THEIR TREATMENT. FOR EACH EVENT, TRY AND REMEMBER YOUR AGE AT THE TIME THE EVENT OCCURRED, WHAT INDIVIDUALS (IF ANY) WERE INVOLVED, AND IF THE EVENT WAS POSITIVE OR NEGATIVE. REMEMBER, THE FURTHER ABOVE THE LINE YOU PLOT AN EVENT, THE MORE POSITIVE YOU CONSIDER THE EVENT TO BE. SIMILARLY, THE FURTHER BELOW THE LINE YOU PLOT AN EVENT, THE MORE NEGATIVE YOU CONSIDER THE EVENT TO BE. WE WILL TALK MORE ABOUT SOME OF THE EVENTS YOU PLOT A LITTLE LATER. IT IS IMPORTANT THAT YOU UNDERSTAND THAT YOUR RESPONSES WILL BE KEPT VERY CONFIDENTIAL, WHICH MEANS NO ONE EXCEPT MYSELF WILL SEE WHAT YOU HAVE WRITTEN. DO YOU HAVE ANY QUESTIONS?



Appendix B

Individual Interview Protocol

1. Knowledge/Communication

(Referring back to the time-line exercise)....

- You noted that you were __ years old when your brother/sister was diagnosed with cancer. Thinking back to that time, tell me how you became aware of the diagnosis and what was told to you.

Prompts:

- *Who initially told you about the diagnosis?*
- *What did they say?*
- *Did you feel it was enough information?*
- *What other information would you have wanted to know at that time?*

2. Initial Concerns/Coping

- a. What were your initial concerns after being told your brother/sister was diagnosed with cancer?

Prompts:

- *Did you have concerns about your brother/sister? Explain...*
- *Did you have concerns about yourself? Explain....*
- *Did you have concerns about your family such as financial concerns, or concerns about day to day activities? Explain.....*

- b. What did you do (if anything) to deal with those concerns?
- c. Were these things helpful?

3. Family Changes at Time of Diagnosis/Treatment

- Still thinking back to when your brother/sister was diagnosed, what things became different in your family, and what was that like for you?

Prompts:

- *Were there any changes in your responsibilities or “roles” at home? Explain....*
- *How did you feel about these new responsibilities/roles?*

4. Other Changes

- Did anything else in your life become different while your brother/sister was receiving treatment for cancer?

Prompts:

- *Did your relationships with peers/friends change during this time?*
- *Did anything in school change for you during this time (e.g., grades, ability to concentrate)? Explain.....*
- *Do you remember any changes in your mood, sleeping patterns, or appetite during this time? Explain.....*

5. Current Functioning (Post-Treatment)/Coping

- a. So far, we have talked about when your brother/sister was diagnosed and what things were like for you at that time. It has been __ years since your brother/sister was diagnosed and been through treatment, how have things changed since then for you?

Prompts:

- *How has your brother/sister's illness affected your relationship with your parents?*
- *How has the illness affected your relationship with your brother/sister who had cancer?*
- *How has the illness affected the family as a unit?*
- *In what ways are you different as a result of your brother/sister's illness?*

- b. You mentioned earlier that you used to have concerns regarding _____, do you still have those concerns?

Prompts:

- *Do you worry that your brother/sister will relapse?*
- *Do you ever fear about becoming ill yourself?*

- c. What do you do when you are worried or concerned? How helpful is that for you?

6. Intervention/General

- a. Looking back on the whole cancer experience, who was the biggest help to you? How were they helpful?
- b. What would have helped you during the initial phases of your brother/sister's illness?
- c. What do you find the most difficult about having a brother/sister who has/had cancer?
- d. Did anything good happen as a result of living with a family member who has had cancer?

Appendix C

Group Interview

1. Knowledge/Communication

- a. When I asked you all to describe how you became aware of your brother/sister's diagnosis, and whether or not it was enough information, some of you stated _____. Did any one else have this experience?
- b. Some of you stated that you would have liked to know _____ about your brother/sister's diagnosis and treatment. Did any one else feel like this information would have been helpful at that time?

2. Concerns/Coping

- a. After talking to each of you regarding what typed of things worried you at the time of your brother/sister's diagnosis, these were the major things you said: _____. Did any one else feel this way?
- b. If you can try and remember back to when you were worried about those things, what did you do that was helpful in dealing with the worry and concern? What wasn't helpful?
- c. Do you all still have these concerns? Why or Why not.....

3. Family Changes

Some of you stated that your family changed a bit during the time when your brother/sister was diagnosed. What do you think was the biggest change in your family? What was that like?

4. Other Changes

When asked about other things in your life that began to change when your brother/sister was diagnosed, some of you stated _____. Did any one else feel this way?

5. Current Functioning

We have talked a lot about what things were like for you all when your brother/sister was diagnosed, and what things were like when he/she was going through treatment. Thinking about how things are for you now, what do you think are the biggest changes in your life (if any)?

6. Intervention/General

- a. When you look back on the whole time your brother/sister was receiving treatment for cancer, who do you think was the biggest help to you personally? In what way?
- b. What was/is the hardest part about having a brother/sister with cancer?
- c. Was there anything positive that happened as a result of your brother/sister being diagnosed and receiving treatment for cancer?
- d. Knowing what you do now about having a brother/sister with cancer, what would you tell other siblings that are just finding out their brother or sister has cancer.
- e. What would you suggest would be the best way to help siblings who are living with a brother or sister that is receiving treatment for cancer?

Appendix D

Parent Protocol

1. Knowledge/Communication

The siblings were all asked about how they became aware of their brother/sister's diagnosis, and whether or not they felt they were given enough information. Tell me about the time when your child was told of the diagnosis and what was told to him/her.

Prompts:

- *Who initially told the sibling about the diagnosis?*
- *Did you feel he/she was given enough information?*
- *What other information (if any) would you have liked to tell him/her at the time of diagnosis?*

2. Initial Concerns/Coping

- a. The siblings were asked to think back to the time of their brother/sister's diagnosis and try to remember specific worries or concerns they had at that time. Can you remember what your child was concerned about after they learned of their brother/sister's diagnosis?

Prompts:

- *Did he/she worry about illness-related aspects (relating to either him/herself or the sick child)?*
 - *Did he/she worry about the family (e.g., financially, logistical concerns)?*
- b. What did he/she do (if anything) do deal with these concerns?
- c. Do you think these things were helpful to him/her?
- d. Do you think he/she still worries about the things that you mentioned?

Prompts:

- *Do you think he/she worries about his/her sibling relapsing?*
- *Do you think he/she worries about becoming ill him/herself?*

3. Family Changes

The siblings were asked to describe changes they encountered in their families around the time of diagnosis and initial phases of treatment. What do you remember being the most significant change in your family during this time?

Prompts:

- *Were there changes in family roles/responsibilities?*
- *If so, how did your healthy child deal with the changes?*

4. Other Changes

The siblings were asked about other aspects in their life that had changed as a result of their brother/sister's diagnosis. When thinking back to that time, what do you remember as becoming different or changing in his/her life?

Prompts:

- *Did you notice changes in his/her relationships with peers?*
- *Were there changes in his/her academic functioning?*
- *Did you notice any changes in his/her mood, sleep, appetite, ability to concentrate?*

5. Current Functioning

The siblings were asked to think about how aspects of their lives have changed since their brother/sister has completed treatment for cancer. What do you see as the most significant changes in his/her life since your child completed treatment?

Prompts:

- *Do you think the illness has affected his/her relationship with you? Explain...*
- *Do you think the illness has affected his/her relationship with his/her sibling who received treatment? Explain....*
- *How do you feel the illness has affected the family as a unit?*

6. Intervention/General

- a. The siblings were asked to identify who was the biggest help to them during their brother/sister's illness. Who would you say was the biggest help to them? How were they helpful?
- b. The siblings were asked to think of what would have been helpful to them at the time of diagnosis and treatment. Can you think of anything that would have helped your healthy child deal with the illness during this time?
- c. The siblings were asked to identify what was the most difficult aspect of having a brother/sister with cancer. What would you say was the most difficult aspect for him/her?
- d. The siblings were asked to talk about positive aspects that resulted from living with a brother/sister who received treatment for cancer. Do you think anything positive happened as a result of your child undergoing treatment for cancer?

Appendix E

Introductory Letter to Parents

July 5, 1999

Dear Parent:

Camp time has arrived! At this year's sibling session, your child will have an opportunity to participate in a research study that will focus on siblings' perceptions of having a brother or sister who received treatment for cancer. The purpose of the study is to gain a thorough understanding of how living with a brother or sister with cancer has affected a sibling's life and overall adjustment. Your child would be one of several siblings chosen for the study, and involvement would include an interview with the researcher during the camp week, a group session with other sibling participants (also during the week at camp), and a phone interview with you. Results from the study will be used to help other siblings of pediatric cancer patients deal with difficult aspects of the cancer experience.

Of course your participation is voluntary. Declining to participate will not affect you or your child's involvement with Camp Ronald McDonald for Good Times. If you choose to participate, all information will be held strictly confidential, and there will be no way to identify you or your family in the study. In addition, you and your child will have the right to withdraw from the study at any time.

As the principle investigator, and volunteer for CRMFGT for several years, I hope you and your child will consider participating in the study that is aimed to help other siblings face cancer in their families. This study has been endorsed by the executive committee of Camp Ronald McDonald for Good Times.

Thank you for your time and consideration. Looking forward to talking with you!

Erin K. Marasca, MA
Principle Investigator

Brain Crater
Camp Director

Appendix F

Consent to Participate in Research Study

Dear Study Participant:

You are invited to participate in a research study. You will be one of approximately 10 subjects in the study. The study will investigate long-term effects of cancer on siblings. The purpose of the study is to gain a better understanding of brothers and sisters of cancer patients who have adjusted to the cancer experience three or more years after diagnosis was made. It will require you to participate in a face-to-face interview and a group interview at this year's sibling session at Camp Ronald McDonald for Good Times. In addition, your one of your parents will also be asked to answer similar questions after the camp session relating to your adjustment via phone. Both the individual and group interviews will be audiotaped and take approximately 60-90 minutes each to complete.

If you agree to participate, a packet of information will be sent to your parents which will provide more information about the study. The information in the study records will be kept strictly confidential. Data will be stored securely and will be made available only to persons conducting the study unless your parents specifically give permission in writing to do otherwise. No reference will be made in oral or written reports which could link you or your family to the study.

Your participation is voluntary. You may refuse to participate, or may discontinue your participation at any time without penalty and without jeopardizing your continued involvement at Camp Ronald McDonald for Good Times. If you withdraw from the study before data collection is completed, your data will be returned to you or destroyed.

We hope that the information we gain from this study will help us understand the long-term effects of pediatric cancer on sibling adjustment so that appropriate support programs can be developed for siblings at risk for adjustment difficulties. It is important to understand that, although the information gathered in the project is intended to be helpful to siblings of children with cancer, some topics included in the study procedures may be difficult for you to discuss (i.e., relating to the cancer experience). We will make every attempt to follow-up on issues of concern during the camp week and thereafter, if needed. We would be happy to share a summary of information collected when the study is complete.

If you have any questions at any time about the study or the procedures, you may contact the principle researcher, Erin Marasca, at (919) 845-4980, or the faculty sponsor, Ann Schulte, Ph.D at (919) 515-1708. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact the Chairperson of the NCSU Human Subjects Committee, Box 7906, NCSU Campus.

I have read the information provided above. I voluntarily agree to participate in the study. After it is signed, I understand I will receive a copy of this consent form.

Signature of Minor

Date

Signature of Parent/Legal Guardian

Date

Appendix G

Background Questionnaire for Parents

Sibling's Name _____

Birth Date _____ Age _____

Grade _____ School Level: _____ Middle
 _____ High School

Family Composition:

- ___ Lives primarily with mother (Occupation _____)
- ___ Lives primarily with father (Occupation _____)
- ___ Lives primarily with two parents
- ___ Lives primarily with one biological parent and one step-parent
- ___ Lives primarily with nonbiological caretaker other than parents

Total number of children in family _____

List gender, age, and date of birth for each child. Place an * by the child who has been treated for cancer.

<u>Gender (male/female)</u>	<u>Age</u>	<u>Date of Birth</u>
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. _____	_____	_____

Please indicate the type of cancer that your child was diagnosed with, date of diagnosis, type of treatment received, length of treatment, and remission status:

Type of cancer: _____

Date of Diagnosis _____

Type of Treatment: Chemotherapy Radiation Surgery
 Bone Marrow Transplant Other _____
 (Circle all that apply)

Length of treatment _____ years _____ months

Remission? Yes No (Circle One)

Is the sibling to be interviewed a biological, half, or step sibling to the child who was treated for cancer? (Circle One)

Appendix H
Project Evaluation

Please indicate how helpful each part of project was to you:

	<u>Not Helpful</u>			<u>Very Helpful</u>	
1. Individual Interview	1	2	3	4	5
2. Group Interview	1	2	3	4	5
3. Timeline	1	2	3	4	5
4. Project as Whole	1	2	3	4	5

What was the best thing about participating in the project?

Is there anything else that you feel would have been helpful in the project?

Did anything happen during the project that you didn't expect?

What did you like best about the leader?

Could the leader have done anything to improve your experience in the project?

Any Comments?