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LIVING WITH CHILDHOOD CANCER:
IMPACT ON THE HEALTHY SIBLINGS

by

Robin Fireman Kramer

THESIS

Submitted in partial satisfaction of the requirements for the degree of

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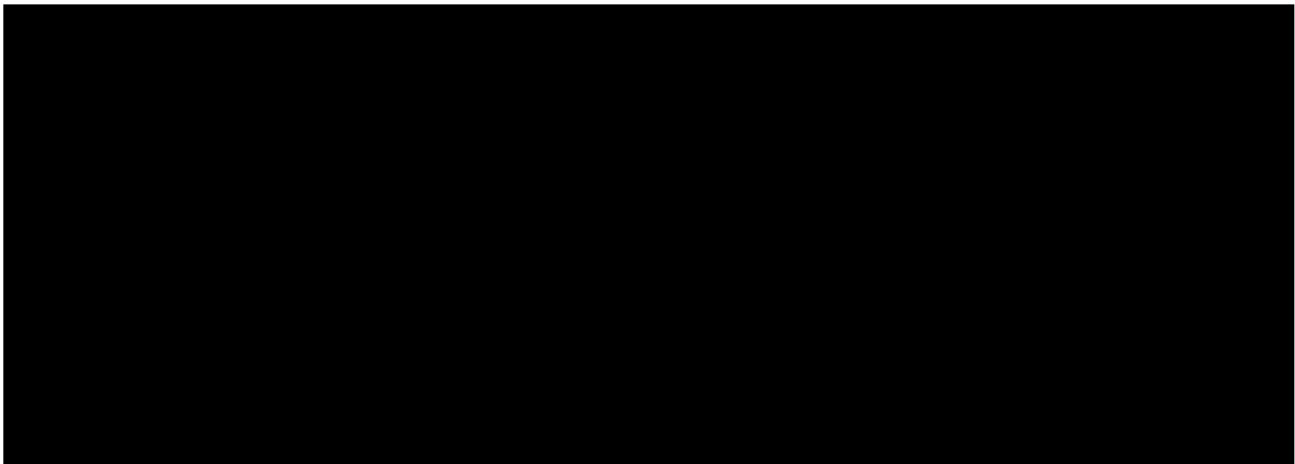
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ABSTRACT

The purpose of this study was to determine healthy children's perceptions of what it is like to live with a brother or sister who has cancer. The research project, exploratory and descriptive in design, was based on interviews with 11 healthy siblings (ages 6-16) of leukemic children. The well children's responses, which were analyzed according to the qualitative method of content analysis, indicated that they experienced three major sources of stress. These included 1) emotional realignment within the family, 2) separation from family members, and 3) family disruptions and changes brought on by the ill child's therapeutic regimen. The illness experience also resulted in positive consequences for the healthy siblings. Their comments indicated 1) an increased sensitivity and empathy for the ill child, 2) enhanced personal maturation, and 3) an increase in family cohesion. The most difficult aspects of living with a brother or sister with cancer were elicited by the question "What advise would you give to other healthy siblings in a similar situation?" The well children identified the following factors as critical in facilitating their adjustment: information about the disease and its treatment, involvement in the cancer illness, and open and honest communication. Overall, the leukemic child's illness had a profound impact on the well sibling's life. The findings suggest that the unique concerns and feelings of the healthy siblings should be acknowledged and taken into consideration when planning care for pediatric cancer patients and their families.

This thesis is dedicated to:

- The 11 healthy children and their families who have shared their experiences in the hope of improving care for other families faced with a childhood cancer illness.
- My brother, Larry.

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CHAPTER I

INTRODUCTION

Statement of the Problem

Major medical advances have been made in pediatric oncology over the past thirty years, significantly altering the prognosis and treatment course of children with cancer. While children once died within weeks of their diagnosis, they can now expect to live disease-free or in remission for several years. "Most childhood malignancies are no longer viewed as 'terminal' but as 'chronic, life-threatening' diseases" (Hartmen, Rudolph, & Johnson, 1977, p. 15).

This improved prognosis poses a new problem to families who must integrate the child's illness and treatment regimen into their daily lives. Personal clinical experience and review of literature have stimulated the researcher to explore the responses and special needs of the healthy siblings of cancer patients, as they have been identified as a particularly vulnerable group for adjustment difficulties.

Statement of the Purpose

The purpose of this study was to determine the impact on healthy children living with a sibling who has a life-threatening illness. More specifically, the study sought to elicit their perceptions of how the illness experience had affected their relationship with parents, the ill

child and peers, and the normal routines of family life. This study also sought to identify the areas in which the healthy children perceived the greatest change and stress. The specific research question being asked was "How do healthy children perceive the experiences of living with a sibling who has cancer?"

Significance and Rationale

The bulk of the literature on childhood cancer consists of retrospective studies which explore the effects of the illness experience on the family during the terminal stage and after the death of the ill child. Although these studies purport to describe the family's reaction, their major focus has been on the ill child and parents, with only tangential mention of the well siblings. Where the well siblings are addressed, the research tends to emphasize the negative responses, alluding to maladaptive behaviors. This study was unique in that it focused on the often-forgotten and neglected member, the healthy sibling. The study also identified both the negative and positive consequences of the illness experience. Unlike the majority of published studies wherein parents subjectively evaluate the impact of the sick child's illness on the well siblings, this study called on the healthy children to speak for themselves. This was important to prevent second-hand interpretation.

Each year more children are surviving their cancer experience and the word "cure" is now becoming a reality. Thus, it is no longer sufficient to help families cope with an impending death; therapeutic efforts must be expanded to include help in coping with a life altered by cancer, its sophisticated treatment course, and the accompanying

uncertainties. This pilot study attempted to expand on previous studies and provide a direction for future research. Increasing the knowledge base in this area will alert nurses to the critical areas out of which maladaptive behaviors may develop, as well as identify areas that may encourage strengths and adaptive responses in the healthy siblings. This information will allow an informed approach to formulating and implementing interventions designed to minimize the negative aspects while capitalizing on the healthy child's adaptive resources. A preventive focus will promote the healthy adjustment of the ill child's sibling(s), supporting the normal course of growth and development.

Assumptions

The following are the primary assumptions upon which this thesis was founded:

- 1) Healthy siblings of children with leukemia are affected in a unique way by the family changes brought on by the cancer illness.
- 2) The healthy siblings will share their personal feelings, concerns, and reactions to living with a brother or sister with cancer.
- 3) Certain feelings, concerns and reactions of the healthy siblings to the cancer illness are similar yet influenced by the illness' course and the family's coping abilities. However, the healthy children's interpretations of their experiences and the significance they place on them are dependent upon their level of cognitive and emotional development.

Conceptual Framework

"Man's experience is largely determined by his interactions with his environment ... and what he experiences depends on both internal and external components" (Minuchin, 1974, p. 21). In conceptualizing this research problem, one must examine the "cancer illness" and the "family system" as pertinent external factors.

The cancer illness, itself, represents a situational crisis which is suddenly imposed upon the family. Trying to cope with the ambiguity of a life-threatening illness challenges the developmental and adaptive tasks of the entire family (Futterman & Hoffman, 1973). "A family has a wholeness or unity because it is made up of interdependent rather than independent parts" (Janosik & Miller, 1979, p. 5). Thus, an illness in one member has a significant and individualized impact on each of the others. No member of a child's family is immune from the stresses an illness brings and no family is left unchanged (Gogan, O'Malley, & Foster, 1977).

Childhood illness causes a shift in the focus of family solicitude and concern, thereby creating a disequilibrium (Parsons & Fox, 1968). Family life revolves around the sick child whose needs become paramount and demand increased parental nurturance, time and energy (Gaspard, 1970; Gyulay, 1978). According to Anna Freud (1968), a preoccupation with the sick child limits a mother's perceptions, hampering her ability to meet the developmental needs of the other children in the family. Thus, it can be inferred that the healthy siblings of pediatric cancer patients are placed in a deprived position.

How the well children will respond within the framework of the above external factors depends upon a crucial internal factor: their perceptions of the experience. Children's perceptions and interpretations of their world are organized and processed according to their cognitive and emotional level of development. "One of the most serious and pernicious misunderstandings about young children is that they are most like adults in their thinking and least like us in their feelings" (Elkind, 1974, p. 51).

Piaget, one of the most renowned developmental theorists, describes cognitive development as a continuous and orderly process, each stage building upon the accomplishments of the previous one. The assigned chronological age ranges are rough estimates, taking into account that each child moves through the phases at an individualized pace. Theoretically, the school-age child (7-11 years) is in the cognitive stage of Concrete Operations, where thought processes shift from inductive to deductive reasoning, becoming increasingly more logical. The child is systematically able to sort out and classify multiple facts in solving problems that before were approached by trial and error (Elkind, 1974). Although children in this stage are capable of formulating hypotheses and assumptions, their cognition is limited by not being able to test them out. Mistaking the hypotheses and assumptions for reality, they either adapt the facts to support their thoughts or ignore evidence to the contrary (Elkind, 1974).

Children in Concrete Operations have a fairly realistic concept of causality, supported by an adult understanding of time (present, past, and future). They come to understand that events are independent of their

internal feelings/motivations and that these events can be explained in terms of external factors (Piaget, 1930).

The increased cognitive abilities of school-age children also enhance their communication skills and interpersonal relationships (Elkind, 1974). They are able to consider the point-of-view of others; they engage in a higher level of communication with a give-and-take approach. Capable of comparing what they hear and see with what they know, they are able to make judgements about truth and falsehood as well as reality and appearance. It is also at this age that children learn to operate by rules, frequently developing a tendency for rigid adherence (Elkind, 1974).

The transition into the last phase of intellectual development, Formal Operations, begins roughly at 11-12 years of age (pre-adolescence) and lasts until about 14-15 years of age (Piaget & Inhelder, 1969). It is during this time that childhood is thought to end and youth begins. The thought processes of children this age undergo a significant change as they develop the ability to think and to reason beyond their own realistic world and beliefs (Maier, 1969). The randomness of their cognitive behavior is replaced by a systemic approach to problem solving which is further enhanced by their ability to not only formulate hypotheses but to test them as well. No longer bound by a concrete, here-and-now orientation, pre-adolescents are capable of both abstract and introspective thinking. These newly acquired cognitive abilities enable youth to philosophize and incorporate into their life the social concepts of fairness and justice, which tend to reflect equity (Maier, 1969).

Piaget's analysis of intellectual development ends with the phase of Formal Operations, implying that the individual's basic pattern of think-

ing and reasoning has been established (Maier, 1969). Thus, by fifteen years of age, the youth can be said to have theoretically reached intellectual maturity. Most, not all, reach Formal Operations at this age, and some never reach it.

In analyzing a child's level of cognitive development, one must remember that every new objective behavior is initially surface behavior. Thus, when children are threatened, they may automatically revert to their previous intuitive and egocentric patterns of thinking and reasoning (Maier, 1969).

According to Erikson's theory of human development (Erikson, 1963), a child's cognitive development is influenced by his/her psychosocial development. Erikson's ideology is similar to Piaget in that it encompasses an evolutionary process. However, Erikson assumes that the emotional aspects of life directly influence all human functions and are the basic core of man's make-up (Maier, 1969). Development is based upon universally experienced biological, psychological and social events, and "involves an autotherapeutic process to heal the scars created by natural and accidental crises inherent to development" (Maier, 1969, p. 29). Erikson has described the natural crisis of school-age children as the challenge of developing a sense of competence and industry while fending off a sense of inferiority. During this phase, participation and performance are very important to school-age children; they have a pervading desire to excel and are determined to master all tasks placed before them. They want and need the continued association of others, relying on their contemporaries to measure their own skills and worth. Fear of failure impels them to work harder; even feelings of mediocrity

threaten a potential inferiority, a feeling that they must stave off in order to move into adolescence with self-assurance and esteem (Maier, 1969).

The major developmental issue of adolescence is the task of developing a sense of identity while overcoming a sense of identity diffusion (Erikson, 1963). "The youth does not question who he is but rather what and in what context can he be and become" (Maier, 1969, p. 58). As an initial step in working towards self-reliance, the adolescent severs the ties of the parent-child relationship and turns to peers for social exchange, emotional support, and value clarification. Adolescents must reconcile their childhood and family dependencies while finding their place within the adult world.

Adolescence has been socially authorized as a period of extended childhood, providing a psychosocial moratorium which delays adulthood (Erikson, 1956). In short, this span of development acts as a psychological safety device which gives teenagers time to mature and cope with the rapid physical and psychosocial changes they experience.

Thus, a child's behavior in response to a sibling's illness is governed by "his unique perceptions of himself and the world in which he lives [and] the meanings things have for him" (Combs & Snygg, 1949, p. 17), all of which are based on his cognitive and emotional level of development.

CHAPTER II

LITERATURE REVIEW

Related Studies

Formal research observations have suggested that healthy siblings experience stress (such as feelings of isolation, anxiety and depression) similar to that of the ill child and of equal or greater intensity (Lansky & Gendel, 1978; Cairns, Clark, Smith & Lansky, 1979; Spinetta, 1981). Therefore, the healthy children facing radical and often prolonged or even permanent changes within the family can be considered "at-risk" for adjustment difficulties. Several of the initial studies which depicted parents' assessment of the well child's reaction to the death of a sibling, found that resulting maladaptive behaviors are frequent.

In one of the earliest studies, reported by Cain, Fast and Erikson (1964), 58 children between the ages of 2 1/2 and 14 years developed psychiatric problems after experiencing the death of a sibling. These children's reactions included distorted concepts of illness and death; fearful and confused attitudes towards doctors, hospitals, and religion; a preoccupation with the dead child through comparisons, identification and misidentification; disturbances in cognitive functioning; and difficulty in coping with parental grief and mourning responses and the changes in family structure.

Binger and colleagues (1969), who interviewed 20 families after the death of a child with leukemia, found that in approximately one half of

them, one or more previously healthy children experienced difficulties during their sibling's illness. Among the problems reported were severe enuresis, headaches, poor school performance, school phobia, depression, separation anxiety, and feelings of fear, guilt and rejection. These symptoms increased after the ill sibling's death. Also, the surviving sibling became preoccupied with the dead child; concerned about being responsible for the death; fearful of being the next to die; and resentful toward parents for their preoccupation with the sick child and their inability to protect him.

Stehbens and Lascari (1974) conducted a follow-up study of 16 families who had experienced a childhood death due to leukemia. Data obtained from parents three months to three years after the child's death revealed that 12 siblings had transient problems such as enuresis, abdominal pain, dysphoria, and restless sleep. Seven siblings had a decline in school performance which lasted several months. Two of the siblings were reported to have had long-term effects: one had a preoccupation with the dead child, and the other, a reluctance to report any illness to her parents in fear that it would be the same as the deceased sibling's. Overall, however, seventy percent of the siblings were considered by their parents to be "back to normal" within a week after the death.

In a similar study, data on the impact of childhood leukemia on the health and functioning of family members was collected from 40 families three months after the death of the ill child (Kaplan, Grobstein, & Smith, 1976). Sixty-five percent of these parents identified problems in surviving siblings related to school, parent-child relationships, and placement outside the home during the illness.

Two research studies sought to determine the long-term impact of a childhood cancer survivor on the family. First, Gogan, Koocher, Foster and O'Malley (1977) interviewed 13 individuals, ages 8 through 28, who were born before the cancer was diagnosed in their siblings (median age at diagnosis was 4 years). Direct interviewing with the well children (which took place an average of 13.5 years after the diagnosis) indicated that the experiences were not remembered as particularly upsetting or traumatic. The researchers suggested that the number of intervening years from the diagnosis to the interview, the young age of the child at the time of the ill sibling's diagnosis and treatment, and suppressed feelings may, in part, be responsible for the study's findings. Providing a second perspective, the authors stated that there is evidence that this lapse in memory is also related to a lack of family openness in discussing the cancer illness. The only long-term effects reported were lingering problems with sibling rivalry and guilt.

More recently, Peck (1979) investigated the problems experienced by 24 families of long-term cancer survivors with either Acute Lymphocytic Leukemia (ALL; N=12) or Wilms' tumor (N=12) who were treated in England. At the time of the interview the ill child had been diagnosed at least 4 years and been off therapy anywhere from 2 to 13 years. Four of the 24 patients were only children. Subjective parental assessment indicated that the siblings in five of the ALL families evidenced behavior problems and feelings of jealousy and parental rejection. In three of the families, the siblings had not resolved their problems at the time of the interview. Seven of the Wilms' tumor families reported the same sibling problems in addition to psychosomatic symptoms and school difficulties.

Five of those seven families admitted that these problems were still present at the time of the interview. Both groups of parents attributed the sibling adjustment difficulties to two factors: overindulgence of the sick child and the mother's separation from her well children during hospitalizations, which often resulted in their being boarded out.

Lavigne and Ryan (1979) addressed the psychological impact on well children with chronically ill siblings, by using an objective tool and comparison groups. Three- to thirteen- year-old siblings of pediatric hematology (N=62), cardiology (N=57), and plastic surgery patients (N=37), as well as a control group of healthy children's siblings (N=37) were assessed for adjustment by parental rating on the Louisville Behavior Checklist (designed to objectively measure children's emotional and behavioral problems). Analysis of the data suggested that, collectively, siblings of chronically ill children were more likely to experience adjustment or behavioral problems than siblings of healthy children. They also tended to develop certain types of disturbances related to social withdrawal and general irritability. An elevated incidence of overall psychopathology occurred in siblings between 3 and 6 years of age. The older male siblings (7-13 years) of hematology patients were more likely to have emotional problems than their female counterparts. The authors reported that there were no differences in the types of adjustment problems displayed by the illness groups; however, the groups did differ in the extent to which the problems occurred. The findings failed to confirm any differential effects of age relationship on adjustments between the siblings of the three groups.

Taylor (1980) conducted a descriptive study concerning the effects of chronic childhood illness on 25 school-age siblings of children diagnosed

with either asthma, congenital heart disease or cystic fibrosis at least 1 year before the interview. Both the parents and well siblings were interviewed, each citing negative and positive responses to the illness experience. Parents reported jealousy, sibling rivalry, anger and hostility, attention-seeking behaviors, and a decline in school performance as well as an increase in nurturance, cooperation, sensitivity and compassion. Two-thirds of the well children's responses indicated that they experienced feelings of isolation, egocentricity, deprivation, inferiority, and inadequate knowledge of the sibling's condition; one-third of their answers revealed an increase in cooperation, empathy, self-esteem, rewards, and cognitive mastery.

Cairns et al. (1979) conducted a quantitative study to determine the impact of childhood cancer on well siblings from 71 families, using the school-age patients as a reference group from which to evaluate their siblings. The patients and siblings were given one or more of the following psychological tests: The Piers-Harris Children's Self-Concept Scale, the Bene-Anthony Family Relations Test, and the Thematic Apperception Test. Statistical analysis confirmed that, like the patients, the siblings experienced severe stress and emotional problems as a result of living with the chronic life-threatening cancer illness. In fact, the siblings evidenced more stress than patients in the areas of perceived isolation, perception of parental overprotectiveness and indulgence of the sick child, fear of confronting family members with negative feelings, and concern with failure (older siblings only). The patients' and their siblings' scores on feelings of anxiety and vulnerability to illness and injury were similar.

Inductive analysis of a pilot study of healthy children's perceptions of a sibling's cancer experience revealed the themes of change and loss by way of at least one of the following: 1) disruption of interpersonal relationships (especially parents, ill siblings, peers), 2) physical distortion of the ill sibling, 3) disturbances in the routines of family life, 4) alterations in the environment (Iles, 1979). Also cited were pride in increased responsibility and parental trust, an increased sensitivity to the ill child's and parents' feelings, a respect for the ill sibling with all that had to be endured, and gains in knowledge and understanding of the physical responses brought on by the disease and therapy. Indeed, the illness experience is not exclusively negative for all, as it also provided opportunities for the growth of the well sibling.

Sourkes (1981) insightfully identified thematic categories which have emerged from her psychotherapeutic work with siblings of pediatric cancer patients. Analysis of case studies indicated that the well children expressed concern about the illness' cause, visibility and treatment process, feelings of guilt and shame, identification with the illness, relationships with parents, academic and social functioning, somatic reactions and the bi-directionality of the sibling-patient relationship. Sourkes stressed the critical nature of the caring sibling-patient relationship which she observed; it was seen as an enriching aspect which facilitated the adaptation of the entire family.

The most recent and multifaceted sibling study was conducted by Spinetta and colleagues (1981) over a 3-year period. The subjects of the study were the siblings of children with cancer, who themselves were part of the larger family-oriented study. First, each family was given a battery of tests (which were not specified) with an assigned

psychometrist judging: 1) the level of each family member's emotional adjustment to the cancer and 2) the family's ability to meet the medical needs of the patient and the day-to-day needs of each family member. At the end of the 3-year study period, the hospital-based extended health-care team members completed the Family Adjustment Scale (FAS) which was devised specifically for the study. This scale is an item-specific series of criterion measures with responses that can be scored objectively in six categories. When the responses to each category of the FAS were compared to the psychometrist's initial judgements, a significant correlation existed, indicating that both measures had tapped the adjustment of family members to the cancer experience. The study results showed that the siblings' emotional needs were met significantly less adequately than those of other family members.

During the same 3-year period, a series of additional tests were administered to each sibling and patient in various settings and disease-related circumstances. Sibling responses were reported as follows:

Children aged 4-6. Siblings demonstrated a lower self-concept (the Brown IDS Self-Concept Reference Test) than patients in the same age group. They also showed a greater sensitivity toward the patient than did the patient toward the well sibling. Lastly, the siblings viewed their parents as more psychologically distant from themselves than did the patients.

Children aged 6-12. The school-age siblings scored at levels indicating significantly less adaptation during the diagnosis period, during periods of relative stability of the disease, and when the disease was in

long-term (greater than 5 years) remission. A story-telling test (Roberts Apperception Test) identified the siblings as being more maladaptive in items related to anxiety, depression, and maladaptive responses. This age group also viewed their parents as more psychologically distant from themselves than did the patients.

Children aged 13-18. The adolescent siblings scored their families (as measured by the Family Environment Scale) both significantly greater in conflict and lower in cohesion than did the same-aged patients. Siblings also scored higher than the patients on the conflict measure of the Roberts Apperception Test.

Spinetta (1981), and Spinetta, McLauren et al. (1981) reported the use of an additional assessment tool, a revised application of the Kinetic Family Drawing (KFD-R). This tool (carefully defined, well delineated and structured) was cautiously interpreted as a supplementary instrument useful in measuring patients', siblings', and parents' feelings and attitudes toward the cancer experience. Three or more drawings were obtained from the individual family members in 90% of the cases. The siblings' scores indicated a more maladaptive adjustment as the ill child's pain increased. The researchers suggest that this may reflect the full support parents give the patient during these crisis times, leaving the siblings with little attention and support. In fact, the other evaluative measures indicated that the siblings scored at their worst when the parents and ill child were doing relatively well. Thus, the siblings are neglected during times of crisis when parental attention is focused on helping the ill child through the traumatic episode. And, during the uneventful periods when the patient is doing well, parental

concerns shift to other non-disease related matters and the siblings are again left without support (Spinetta, 1981).

Summary

The preceding literature review cites studies on the multiple reactions of siblings of children with cancer. Since children with cancer previously died of their disease within a short time from their diagnosis, the earlier studies focused primarily on the effects of the death on the surviving siblings. However, as the prognosis has improved for certain childhood cancers (leukemia being one) clinical studies must address another issue: what is the impact on healthy children living with a sibling who has cancer? The aim of this pilot study was to begin to answer that question with the hope of uncovering the unique perspective of the healthy brothers and sisters of pediatric cancer patients.

Leukemia

Before proceeding with the study's methodology, the author would like to provide a brief discussion on leukemia. This will give the reader a basic understanding of the disease and assist in the assimilation of the study's findings.

Leukemia is frequently referred to as cancer of the blood. More specifically, it is cancer of the white blood cells (leukocytes). The disease is characterized by an abnormality in the white blood cells (WBCs) which hinders them from maturing as expected and renders them unable to carry out their normal immunologic function - protecting the body against disease-producing bacteria, viruses and fungi. These

immature WBCs, which multiply abnormally and uncontrollably, crowd out and displace other essential components of blood, like platelets and red blood cells, so that there are inadequate numbers to prevent bleeding or provide gaseous transport.

The presenting signs and symptoms, which can have an abrupt or insidious onset, reflect the abnormal maturation and proliferation of WBCs. Leukemic children often don't seem like their usual selves. They tire more easily and look pale as a result of anemia (inadequate production of red blood cells). An increase in bruising, petechiae, and bleeding of the gums becomes evident as their platelet count is compromised (thrombocytopenia). A lingering low grade fever, with or without an obvious source of infection, may occur because of a lack of normal WBCs (neutropenia) or because of the leukemic process itself. The overgrowth of abnormal WBCs in the bone marrow, where all blood cells are made, frequently causes bone pain.

Leukemia often is suspected by identifying "blasts" (abnormal leukocytes) in the peripheral blood sample from a complete blood count (CBC). Sometimes "blasts" may not show up in the blood even though the bone marrow is full of them. In such cases, suspicion of leukemia must be confirmed by analysis of a bone marrow aspiration for "blasts".

Although there are several types of leukemia seen in children, acute lymphocytic leukemia (ALL) is by far the most common. It accounts for 85% of all childhood leukemias. ALL is typically diagnosed in children between the ages of two and eight years.

Prompt and vigorous treatment is necessary to prevent abnormal proliferation and the spread of leukemia cells to other areas of the body.

Cranial radiation and chemotherapy are the two major modalities of treatment and are carried out primarily on an outpatient basis (therapy will be discussed in an upcoming section). Of all childhood leukemias, ALL carries the best prognosis: Ninety percent of children go into remission (leukemia-free state) within the first four weeks of therapy (Simone, 1974). Because of the therapeutic advances occurring the last decade, at least 50% of these patients can be expected to achieve a long-term five year leukemia-free survival (Miller, 1980).

CHAPTER III

METHODOLOGY

Design

Although a fair amount of literature "theorizes" on the well children's unique response to living with a sibling who has cancer, few formalized research studies, focusing solely on siblings and using them as primary informants, have been conducted to substantiate those statements. Iles' study (1979) is one of the few studies which provides empirical evidence on siblings' reactions. The exploratory descriptive research design used by Iles served as a model for this study, in answering the question: "How do healthy children perceive the experiences of living with a sibling who has cancer?"

Exploratory research, which is conducted early in the investigation of a problem, is concerned with the discovery of important variables and the relationships among those variables (Polit & Hungler, 1978). It also allows for the clarification of concepts and the establishment of priorities for further research (Selltiz, Wrightman, & Cook, 1976). "Exploratory research is most needed in scientific areas where the purpose is to answer general questions and develop specific hypotheses" (Krueger, Nelson, & Wolanin, 1978, p. 196).

This study can be further classified as naturalistic field research since the investigation took place in real social settings, examining phenomena as they naturally occurred (Polit & Hungler, 1978). A small

sample size was used which reflects the researcher's intent to obtain indepth information that could serve as the basis for future research in this area.

Sample

The population under study consisted of healthy school-age and adolescent siblings of pediatric leukemia patients being treated in the outpatient oncology clinic at University of California Medical Center, San Francisco. Convenience sampling was used to obtain 11 children as research subjects. Criteria for selection was based on the following:

1. Siblings of the leukemic child must be between the ages of 6 and 16, inclusive. All age-appropriate siblings in the family were asked to participate in the study.
2. The ill child (18 years old or younger) must have been diagnosed at least 6 months before the interview and never have had central nervous system disease.
3. The siblings must be part of a two-parent family, be living in the same home as the ill child, and not be under treatment for any significant health problem.
4. The parents and siblings must speak English (Assistance will be provided if parents are unable to complete the self-administered questionnaire).

The researcher did not try to control for the siblings' race, religion, sex or birth order in relation to the ill child.

Statement of Access and Protection of Subjects

Access to subjects was gained through the Pediatric Oncology Department at the University of California Medical Center, San Francisco. Permission to use outpatient families was obtained from all members of the pediatric oncology team.

Review of medical chart records, based on a list of children with Acute Lymphocytic Leukemia, resulted in a final list of families meeting the criteria for inclusion in the research study. Each of these families was contacted by phone by the Pediatric Oncology Nurse Specialist who briefly explained the nature of the study and asked permission to make their names available as potential subjects. The families that agreed to be approached were mailed an introductory letter (Appendix A) from the pediatric oncology team which included a copy of the permission/assent forms (Appendices B and C). Approximately 3 days following the receipt of this letter, the researcher contacted the family by phone to answer further questions and to find out whether they would agree to participate. If the family agreed, a mutually convenient date was set up to meet either at their home or at the clinic.

The benefits and risks of the family's participation are clearly stated in the permission/assent forms. The major benefit was described as helping health care professionals recognize and more fully understand the needs of pediatric cancer patients' siblings. With this information, they, in turn, can counsel parents in meeting the well children's needs, thereby better supporting their coping and adaptive responses. A second benefit cited was the possibility of a therapeutic effect on the well

sibling, as it would single out the child as an important member of the family while allowing him/her a chance to express feelings and concerns.

The major risk cited was the potential for child and/or family discomfort caused by uncovering previously suppressed feelings and concerns. If it became clear during either the sibling or parent interview that follow-up was advisable, the researcher would discuss the problem with the parents, suggesting that Dr. Ablin (the Attending Pediatric Oncologist) be consulted for assistance. If the parents agreed to have the researcher contact Dr. Ablin, then the pediatric oncology team would address the problem and make the necessary referrals. These plans were developed in conjunction with Dr. Ablin and the pediatric oncology team.

An explanatory letter was attached to the demographic and background information questionnaire that parents were asked to fill out during their child's interview. The purpose of this 15-minute questionnaire and a statement indicating the parents' right to inquire about the necessity of any question was explained in the letter. Parental consent for participation was obtained in the consent form and implied by their completion of the questionnaire.

Data Collection Tools

A parent questionnaire and brief interview guide, and a sibling interview guide (Appendices D and E) were used to collect data. Each of these tools was devised by the researcher.

Parent Questionnaire and Interview Guide

The parent questionnaire and interview guide contain structured and semi-structured questions designed to collect demographic data to account for extraneous variables that would threaten the study's validity, and to query the parents about any maladaptive behavioral changes noted in the well sibling since the leukemic child was diagnosed (so appropriate help could be sought). The questionnaire was self-administered during the healthy sibling's interview. Following the sibling interview, it was scanned by the researcher to check for completeness and clarity. Following this, the researcher interviewed the parent for 15 minutes, asking four questions which did not lend themselves to a questionnaire format.

Healthy Sibling Interview Guide

The interview guide for the healthy siblings consisted of 20 open-ended and semi-structured questions aimed at eliciting the children's perceptions of how the illness experience had affected their lives. The questions were specifically designed to address the perceived changes within the "family system". Each child's responses were probed for clarification and further elaboration. The interviews were approximately one-hour in length and were tape-recorded to provide verbatim data which would ensure accuracy and completeness of the recording of information.

All of the data collection tools were reviewed by Dr. Eugenia Waechter whose expertise and major research endeavors are in the area of childhood cancer. No formal large-scale testing of the sibling questionnaire for reliability or validity has been done. However, it was

pre-tested on a child whose personal situation is similar to that of the subjects under study. This pre-testing also helped determine the questionnaire's clarity, research adequacy, administration length and freedom from bias.

Data Collection Process

Each visit began with the researcher introducing herself and providing background information about her interests in pediatric oncology and the present study's development. The nature of the study and its purpose were explained to the children and their parents. A special effort was made to include the leukemic children in the introductory remarks so that they could better understand the study and why their brother or sister had been chosen to participate. Hopefully, this prevented any feelings of exclusion that might have otherwise occurred.

Next, the permission/assent forms were signed, and the researcher read aloud the sibling form in case the children had difficulty reading. The children were told that they did not have to answer any questions which made them feel uncomfortable and if they wanted, they could end the interview at any time. The parents were asked to complete their questionnaires while the children were interviewed in a separate room. This measure was designated to protect the child's right to privacy. After the sibling interview was completed, the researcher met with the parents to go over their questionnaires. At this point, most parents expressed a curiosity about their children's responses (i.e., "How did he

do?", "Was she helpful?") and asked if they were having any particular difficulties. In no instance did the researchers feel the child was in need of outside help in dealing with the sibling's illness and each parent was reassured that their child had no serious difficulties. It was explained that the healthy child's comments and reactions were similar to those of other brothers and sisters of pediatric cancer patients. The researcher offered to share the final report of the study's findings with all parents. Those parents who inquired about specific responses were reminded that the researcher was not able to disclose the specific content of the interview without the child's consent. Parents were encouraged to talk with their children if they wanted further information.

At the end of the visit, the researcher, acting more as a counselor than an investigator, offered suggestions on how to deal with particular areas of shared parental concerns and possible future problems. Positive reinforcement was given to behaviors which appeared to have facilitated the healthy sibling's adaptation. Lastly, parents were encouraged to contact the researcher or Dr. Ablin if any further questions or concerns should arise.

Analysis of the Data

The parent questionnaire and interview were analyzed for demographic data and other information which might influence the study's findings.

The healthy siblings' transcribed interviews were subjected to content analysis, a qualitative method which categorizes and summarizes

data while identifying recurrent themes and tendencies (Brink & Wood, 1978). Both the substantive content of the subjects' responses and the feelings/attitudes conveyed by respondents were analyzed. The researcher defined all categories, specified a rationale for their development, and demonstrated their appropriateness within the context of the data (Brink & Wood, 1978). The validity of the identified categories was verified by experts in the field of childhood cancer (Dr. Eugenia Waechter and Gail Perin, R.N., M.S.) and content analysis (Drs. Laura Reif and Marilyn Savedra).

CHAPTER IV

PRESENTATION AND ANALYSIS OF DATA

Demographic Data

The demographic data was analyzed descriptively to provide the reader with the context of the healthy siblings' responses. Information on the family structure and the characteristics of family members will be presented in this section. Data covering the families' utilization of health care services appears in later sections which deal with three different topics: separation, hospitalization, and clinic visits.

Family Constellation

A total of nine families participated in the study: seven families had one healthy sibling within the 6-16 year old range, while two families had two well children within this range. A total of 11 siblings were interviewed. As the criteria for inclusion specified, the healthy siblings all came from families with two-parents. Except for one child who was living with his natural mother and a step-father, all siblings lived with their biological parents. The mean age of parents was 37 years with a range from 25 to 47 years. The parents were a highly educated group with an average of two years of college. Three parents held Master's degrees and three parents had high school diplomas.

The mean age of the leukemic child at the time of the interview was 9 years. Seven were females and two were males. The average length of time since diagnosis was 36 months; the overall range was from

8 to 66 months. The mean age of the healthy siblings at the time of their interviews was 10 years. Seven children were between 7-11 years (school-age) and 4 children were between 12-16 years (adolescents). The mean age of the well child at the time of the ill child's diagnosis was 7 years with a range between 2 and 15 years. Five of the healthy siblings were males and six were females; seven were older than the ill child, three were younger, and one was a twin. Table I summarizes characteristics of both the ill children and their healthy siblings.

TABLE I

Demographic Data - The Ill Children and Their Healthy Siblings

I.D.	WELL CHILD		ILL CHILD	
	Age	Sex	Sex	Age
*1	10	M	F	9
*2	7	M	F	9
3	7	M	F	3
4	11	M	F	3
5	7	F	M	11
•6	15	M	F	10
•7	16	F	F	10
8	7	F	M	5
9	14	F	F	12
10	11	F	F	13
11	12	F	F	12

- * - siblings from one family
- - siblings from one family

Healthy Sibling Interviews

Qualitative analysis of the healthy siblings' interviews lead to the following four major categories: Negative Aspects, Positive Aspects, What Has/Would Have Helped, and Advice to Other Healthy Siblings. The latter three categories will be summarized and analyzed using quotes to illustrate key concepts.

Coding the "Negative Aspects" became extremely complex as numerous themes and subthemes emerged and, in many cases, they were interrelated. Thus, a framework was developed to organize and present this data (see Figure 1).

Inductive analysis led to the identification of three major stresses on the healthy siblings as a result of their brother or sister's illness. Each stress (which is defined within the context of the cancer experience) was further subcategorized into three negative consequences with associated sibling emotional responses. Quotes from the well children will be used extensively to substantiate and capture the essence of each category.

Figure 1: Negative Aspects Model for Healthy Siblings



Negative Aspects

Stress #1: Emotional Realignment

Families respond to the diagnosis of childhood leukemia with shock and disbelief. Unexpectedly their lives are completely disrupted by this invasive and threatening event. Family unity is challenged with each member absorbing the impact of the illness according to their cognitive and psychosocial level of development, and the role relationship they share with the ill child.

The bond between a parent and child, laced with emotion since conception, is very strong. And, because of the present day widespread

understanding of the seriousness of the illness, parents tend to respond intensely with anticipatory grief. They feel devastated by the possibility of losing a child and painfully helpless in the face of this uncertainty. Because parents often view children as extensions of themselves, they experience their child's illness as an assault to their own self-image as well as their role of omnipotent protector (Share, 1972). Given this situation it is understandable that the sick child often becomes the central figure in the family. The illness demands enormous amounts of physical and emotional energy for everyone concerned, but especially for the parents. A triad forms between the mother, father and ill child, while the healthy siblings are left in the periphery. The well children interviewed for this study were keenly aware of this shift in family dynamics which significantly changed their relationship with their parents and their ill siblings. They talked openly about their parents preoccupation with the ill child, indicating this emotional realignment as a major source of stress. Analysis of sibling responses revealed that they experienced three major consequences of emotional realignment within the family: emotional deprivation; a decrease in parental tolerance; and an increase in parental expectations.

Emotional Deprivation. The children spoke candidly about the emotional deprivation they felt: "My parents treat him nicer because he's sick"; "They favor N. because they feel sorry for her." One 10-year-old brother tried to rationalize his parents' behavior: "They had to treat her nicely because she was going to have a real tough shot in the marrow." When asked if they had advice that could be shared with other well siblings whose brother or sister was just diagnosed with leukemia,

a 11-year-old girl said, "Expect not to be cared for a lot of the time because everyone is busy with the sick child; nobody really pays attention to you." Displays of parental partiality were particularly distressing to one well child who was a twin: "My mom and dad still are kind of partial to L. Every night they come into her room and talk to her and kiss her goodnight. They don't come into my room - well sometimes my mom will. She tells me 'Don't think we are partial to L.' But it still makes me think they don't care about me and don't love me."

The majority of the children felt that the inequality in treatment was more pronounced the first several months after the diagnosis and gradually improved with time: "A. used to get a lot of attention and I wasn't getting any. But it's better now. They treat us just about the same."

This preoccupation with the sick child was not limited to parents: "Even my grandma, who used to be partial to me, forgot me sometimes, once L. got sick." Another child expressed an overwhelming sense of abandonment and deprivation: "I just got really upset because nobody did anything for me and nobody took me hardly any place. It was like people forgot about me. Everywhere I'd go they'd say, 'How's your sister doing?' Nobody ever asked about me."

Decrease in Parental Tolerance. The children's responses indicated that the emotional realignment was also responsible for parents being less tolerant of their behavior in comparison to their permissiveness with the ill child: "He could do whatever he wanted and have anything he wanted"; "Sometimes R. would get away with stuff that there's no way

I could get away with." This decrease in tolerance of the well child's behavior was mostly evident in regard to discipline: "If N. did something wrong, my mother would let it pass, but if I did something wrong, my mother would really get upset and yell." This same well sibling used her adolescent cognitive abilities to try to cope with this situation by attributing parent overreaction to pent up anxiety over the ill child: "Because they have this on their nerves, they take it out on you." A younger child (7-years-old) assigned a more concrete cause to the unequal discipline: "Sometimes when he hits me I get a spanking and he doesn't because with his cancer, he can get bruised."

This more lenient attitude toward the sick children enhanced their ability to successfully manipulate many situations in their favor. Six of the informants commented on the ease with which the ill child could capitalize on his/her sick role: "Whenever we fight, she'll get the good end and I'll get the bad end." Another child explained that if the ill child did not get what he wanted, he would start crying; which really upset her parents. Consequently, he learned that by just crying, he would get "to stay up later and watch more TV." Although frustrating, this manipulation tended to be more easily tolerated during the several weeks following diagnosis: "In the beginning I was waiting on her hand and foot all the time - I wanted to help her. But I got a little upset because when you asked her to do stuff she'd flat out say no. But it's not like that now; things are more normal." However, all of the well children felt that their brother or sister was still able to influence their parents because of the illness. Even though it had been four years since the diagnosis, one sister explained: "C. kind of expects that people will

do things for her ... she doesn't hardly have to do anything for herself."

Increase in Parental Expectations. The well siblings felt the extra demand of chores which the ill child was frequently excused from doing. Although this was more of a problem at the onset of the illness, two children felt that they still (9 months and 4 years respectfully) were expected to do the majority of chores: "If something needs to be done in the house, like folding the laundry, my mom will usually tell me to do it, more so than L." The other child explained, "We are supposed to do dishes two times a week each but I always end up doing it four times a week. We're also supposed to help clean the house and feed the animals, but H. never has to do any of those things." Manipulation was also used to get out of helping around the home. In this same family, the well sister said, "It used to upset me a lot when H. would say 'I can't do anything because I have leukemia'. She used that as an excuse more so in the beginning but she doesn't use that as often anymore."

The healthy siblings also felt pressure from their parents who had specific expectations about how the well child should treat the ill child: "We had to treat her more better because she has leukemia"; "If I hit him I couldn't play the rest of the day. That's the rules in our house"; "N. could hit me but I wasn't allowed to hit her back. I couldn't fight with her. I had to be totally nice to her and it was kind of bugging me. But if I got mad my mom would say, 'What do you think you're doing? Your sister is sick and could even die. Don't you feel guilty?'"

Four children spoke of the parental protectiveness of the ill child which determined strict play and roughhousing rules: "Sometimes when I play with D. my dad yells because he thinks I'm too rough or that she may hurt herself"; "If L. has a bruise, my parents would come and ask

me if I did it. It makes me mad that they thought I'd try to hurt her or something."

Perhaps the greatest parental expectation of the healthy siblings is that they should tolerate and understand parental permissiveness, overindulgence and preoccupation with the ill child. Some parents are explicit in explaining their behavior to the well children: "Mom says she pays more attention to L. because they may not have her as long." Other parents give messages that are more subtle: "Like if my mom has a choice of leaving me or N. to baby-sit or letting N. do something, N. gets to go because she missed out on some good years of her life or something like that." Another informant explained the futile nature of the situation: "There were times when it was hard not to say anything, like 'Mom I needed this or can we do this,' knowing that she couldn't. It was hard not to ask." Both of these last examples come from adolescents whose cognitive abilities helped them rationalize their parents' biases.

Sibling Emotional Responses

The stress of the emotional realignment within the family, although more pronounced at the beginning of the illness, was still felt close to a year later, and even longer in some instances. The changes that occurred as a result of a shift in the way the family members related to each other, evoked a multitude of emotional responses in the well children.

To begin with, normal sibling rivalry became intensified. The well children specifically used the adjectives "mad", "frustrated" and "jealous" when describing how they felt when 1) they did not get as much parental

attention, 2) the ill child got special treatment and hardly ever got in trouble, 3) they had to be nice to the ill child; otherwise they would get in trouble and 4) they did not get any presents or special favors. One well adolescent remembers that when she was about 8 or 9 years old, she thought, "Hey, it might not be that bad to get leukemia'. But then she'd go and get pneumonia and be sick and I'd say - 'No way.' I don't know why I thought that, you know." This response is understandable in light of the negative consequences resulting from the stress of emotional realignment; and it reflects the school-age child's concrete level of cognition. Well siblings also felt anger and frustration toward the ill child for not appreciating or reciprocating considerate treatment. When one sick child told her sister that she didn't know what it was like to have leukemia, the well child said she became mad because she thought she had been "pretty understanding with N." In her anger, she replied, "Well, you don't know how it feels to be a sister of someone who has leukemia."

The age of the well sibling at the time of diagnosis seemed to influence their responses to this study's questions. There was less anger and jealousy voiced by two of the younger children who were 2 1/2 and 3-years old when their ill sibling was diagnosed. They were less verbal than the older subjects and had a hard time remembering how they felt. In terms of the adolescents, as noted before, it seems as though they used their cognitive ability to both analyze and rationalize their anger and jealous feelings. For example, one teen said she coped with her frustrations by trying to understand what's going on: "It's bad enough she has leukemia. I don't think I was jealous because I thought it was

so scary for her having it [leukemia], no matter how many presents she gets, it doesn't help her anyway, except maybe to cheer her up a little." Another child, now an adolescent, recalls how she felt 4 years ago when her sister was diagnosed: "I didn't get as much attention from my mom and dad. At first I thought 'Hey that's not fair' but then I realized - wait a second, I don't want this to happen to me. Now, though, I've just accepted the fact, that's the way most parents are."

Rejection was another feeling which arose from the emotional deprivation and inequalities the well children experienced. They spoke of partiality and favoritism toward the ill child, of "not feeling loved" and "not being cared for." One child said, "Sometimes I just feel like running away." Although no test was used to evaluate self-esteem, it seems likely that the healthy siblings are a high risk population for a lowered self-concept as a result of the illness experience.

Closely linked to the healthy children's feelings of anger, frustration and resentment was an overwhelming and tormenting sense of guilt. First, they regretted the ways in which they treated the ill child before the illness: "At first I felt a little guilty because I did get in a fight with her right before she got sick. Even though we made up, that's one of the first things I thought about. You can't help but feel bad about it." The typical fighting that occurs between an older brother and younger sister was particularly troublesome for one teen, once he learned his sister had leukemia: "Before she got sick we used to get in fights all the time, probably every day. Now I feel bad about it, like I shouldn't have done it." Several children expressed guilt for being the healthy child: "When I first found out about N. having leukemia, I thought 'Oh,

I'm the big sister, I should have gotten it instead of her.'" Being healthy also took away their right to complain: "Nothing's happened to me so I shouldn't even complain." This guilt over being healthy included feeling bad about going out to play and having fun while the ill child was confined to the house: "Many times I felt guilty to leave her there and go out with my friends, but I did. I felt bad because she couldn't go out and have fun." And when the ill child felt better and was more active, the well children, still trying to stave off guilt feelings, felt compelled to play with them or let them tag along: "Sometimes when she wants me to go swimming with her I really don't want to go. But I usually end up going because I think about the times she is in the hospital and can't go and I can. I feel guilty because I can swim whenever I want and she can't." Another child described a feeling of vacillating guilt: "When R. wants to go with me down the block to my friends, sometimes I take her but sometimes I won't. I just tell her, 'R. you can't come.' When I think about it, because she has leukemia, I feel bad. It makes me want to go back and get her. But sometimes, it doesn't even bother me."

Perhaps the most burdensome form of guilt for the well children was associated with the anger and resentment they felt toward the ill child: "I'm nicer to her now and it makes me feel good, but sometimes she is mean to me. I feel bad but I just rub it off. I don't do anything because if I did, it would make me feel even badder"; "I try not to be mean to her but I know I am and then I feel really bad"; "For the first couple of weeks when she acted bratty, I didn't say anything to her or dare get mad at her. But then, once she could help too, I guess I decided I could get mad at her."

Working through these feelings of anger and guilt, and allowing oneself to feel angry and ambivalent and even to fight with the ill child was quite painful for the well siblings. It seems as though there was one crucial factor which intensified their guilt - a fear of the ill child's death: "I worried that something would happen before I got to say, 'Hey I love you.'" Another child openly recognized the source of her guilt feelings: "I feel like I could be doing the wrong thing by not playing with her because she may not be here some day." An adolescent expressed the same feeling but more subtly: "You never know what can happen, so you should take what you have today and care for it."

Eight of the children talked openly about their fear of the ill child dying: "It shocked me when I found out she had leukemia. I was really scared, I thought she was going to die." An older girl remembers 5 years ago when she learned of her sister's illness: "Fearing that she might die, that was what upset me the most. Now I'm not so hung up on death and everything, but back then, I was just freaked out." All of the children who talked about the leukemic child's possible death were at least 9 years of age, except for one 7-year-old brother. He said that when visiting his sister in the hospital 3 years ago, he "was sad. She was sick and I thought she would die for a minute." This same child now worries about her possible relapse and death.

Another 7-year-old talked about how "scary" it was to see his sister get "IVs" and have blood "taken out." He remembered a character on television who had been shot with a gun and another character said, "He's losing too much blood and he's going to die." This young boy's fears revolved around the misconceptions of losing too much blood from

an IV which "could make you die with leukemia." Apparently, however, his fear of his sister dying had nothing to do with her illness as he said, "The worst thing is that the doctor doesn't really know what leukemia is and she would have it the rest of her life until she died, and that would be sad." To this 7-year-old, death was equated with violence and/or old age which is a typical response of children his age (Nagey, 1959).

Among the subjects questioned, there were three (all 7 years old) who did not speak of the ill child's possible death. Also, these three made no reference to feeling either guilty or bad for the way they treated the ill child or the jealousy/anger they felt. It cannot be assumed, however, that they did not experience some form of guilt feelings or fear for the ill child's well being; rather, it seems likely that their age related cognitive abilities limited their expression of feelings.

Stress #2: Separation

The second major source of stress identified from the healthy siblings' interviews was separation from the rest of the family. These periods of isolation occurred as a result of the sick child's hospitalizations, frequent clinic visits, and the parent's general preoccupation with the ill child.

Hospitalization: Hospitalizations separated the healthy children from their families on an average of twice during the illness course with a range of one to four. All of the ill children were initially hospitalized at the time of diagnosis for a complete physical work-up and the start of their cancer therapy. The primary reasons for subsequent hospitalizations included: 1) blood transfusions, 2) IV antibiotic therapy for

infection, and 3) close supervision for fever (of unknown etiology) and neutropenia (low WBCs). The mean length of separation per hospitalization per well sibling was 7 days for five children, 10 days for one child, and 14 days for three children; And all of the mothers reported staying with their ill children in the hospital for the duration of each admission. Table II summarizes the ill child's total number of hospital days, who supervised the well children during the mother's/parent's absence and the number of hospital visits made by the well children.

TABLE II
HOSPITALIZATIONS

<u>Family</u>	<u>Total Hospital Days</u>	<u>Substitute Caretaker</u>	<u>Total Sibling Visits</u>
*1	16	Grandparents (GP)	1
2	13	GP	1
3	30	Father + GP	3
4	21	GP	0
*5	14	Father	4
6	15	GP	2•
7	20	Friend	1•
8	31	GP	1•
9	22	GP	1

* - 2 healthy siblings per family

• - only saw parents; unable to visit with the ill child

Grandparents assumed the majority of responsibility for care of the well children in the grandparent's home. In most cases, the father had more contact with the well children than did the mother, as he needed to continue working. Phone contact was the most frequent means of keeping in touch with the well children; physical contact was infrequent. The major obstacle to periodic trips home or visits to the hospital by the siblings was the distance each family lived from the hospital. The mean

one way traveling distance to the hospital was 119 miles; the closest distance was 15 miles and the farthest distance was 360 miles. Also, age restricting visiting rules interfered with the well children visiting the ill child in the hospital. Three children who came to the hospital were able to only see their parents, as they were restricted to the waiting room area. Seven children visited with the ill child in person. One child never visited the hospital.

Clinic Visits: Since ALL is treated on an outpatient basis, the majority of therapy was given during routine scheduled visits at the pediatric oncology clinic which is held Tuesday afternoons and Friday mornings. In eight instances, private pediatricians near the families home agreed to help manage the child's care, reducing the burden of frequent trips to San Francisco. On clinic days, parents relied on grandparents and friends to help supervise the well children. In one family, the well child (who was not yet in school at the time of the therapy) regularly accompanied the mother and ill child to the clinic. In another family, the well children (ages 14 and 15) were old enough to be self-sufficient. A third family made special arrangements to receive their outpatient care at the pediatric oncologist's private practice (which was near their home) while the well child was in school.

Parental Preoccupation with the Ill Child: While the ill child was undergoing therapy, parents developed a general preoccupation with him/her. They tried to learn about the disease and its management, while meeting the day-to-day physical and emotional needs of the ill child. A complete blood count (CBC), done at an outpatient laboratory at a nearby hospital, was frequently required to monitor the ill child's

response to therapy and to determine whether CBC values were high enough to safely receive the next course of chemotherapy. Throughout the ill child's therapy, certain oral medications were given daily by the parents at home. While on prednisone, the child's appetite drastically increases and his/her salt intake must be limited to prevent water retention. Eating in general tends to become a focus of parental concern; it is an important aspect of the child's cancer therapy over which parents have direct control.

In addition to over seeing the medical management, helping the ill child cope with the ups and downs of therapy, reentry into school and peer groups, and the unexpected complications which are bound to occur, requires an enormous amount of parental time and energy. The well children are frequently separated/isolated from their families and they are adversely affected by this lack of contact. Analysis of their responses indicated that they experienced: 1) a lack of information, 2) a decrease in involvement with their parents and the ill child, and 3) insufficient social support.

Lack of Information. The diagnosis or even a strong suspicion of leukemia necessitates immediate hospitalization which separates the family and interferes with communication. Many of the well siblings, learning of the diagnosis from parents, either over the phone or several days after the fact, felt the information was incomplete: "No one told me what was happening. I never saw them because they were in San Francisco and I had to stay with my grandma." Also, the little information that was initially given was distorted by misconceptions of the disease: "I just thought it was a cold or something and she'd get healed

fast"; "I thought it was a disease that would go away really easily." Other children said they had no idea what "leukemia" was but because of parents reactions, they knew it was serious: "They said she had leukemia and my mom started crying. I didn't know what it was, so I didn't cry." One adolescent, not knowing what leukemia was, looked it up in the encyclopedia (not always an accurate or up-to-date source) and went to his older sister for clarification.

Analysis of the subjects' responses indicated that communication gaps were caused by several factors: 1) parents were busy at the hospital, feeling overwhelmed themselves as they tried to find answers to their own questions, 2) because of physical separation, parents frequently relied on the telephone to communicate with their well children; for this reason, their messages were not always as clear or reassuring as they might have otherwise been, and 3) the well children, who could not easily visit the hospital, were rarely included in the initial family conferences, where the primary information is given about the disease and its treatment.

All 11 of the well children talked about how stressful this lack of information was, especially at the time of diagnosis: "That's why it is so hard at first, until you finally get relieved when someone explains everything to you and you finally know what's going on." Another child was concerned that "They weren't telling even me everything."

The lack of early information posed another burden on the well children, i.e., fielding the barrage of questions from family friends and their own peers: "Everyone was asking me questions and I didn't know how to answer them."

Decrease in Involvement with Parents and the Ill Child. A lack of family involvement took on several dimensions throughout the illness course. At the time of diagnosis, the family unit was split up; the parents and ill child were together in the hospital, while the well child was "boarded out" at the homes of grandparents and close friends. As Table 1 illustrates, the well children had infrequent contact with parents and the ill child during periods of hospitalization. These children cited family separation as the "worst part" of the chaotic time surrounding the diagnosis: "I just remember that everybody was always gone a lot and I was always staying with somebody. I only got to go to San Francisco once to visit with them." This lack of contact instilled a fear of abandonment in one child: "It was when I was little and I didn't think they were coming home for a long while."

Even though the well children were relieved when the family was reunited at home, parental preoccupation with the ill child kept them from feeling like integral family members: "My mom has a lot more pressure on her and she is more busy. It's [my sibling's illness is] always on her mind and she worries a lot." This same child went on to explain that because she sensed her mother's preoccupation, she did not feel comfortable asking her for anything, even companionship.

A 10-year-old boy was particularly sensitive to the illness' influence on his relationship with his father: "We haven't been getting together a lot and doing things. Like, we were supposed to make this go-cart but then A. got sick and he just got pretty busy with her things." He continued to explain that he used school to fill the recent void in his life: "Now I'm in school and I have something to do when they are in the hospital. At least I am doing something so I won't get bored."

Having to attend school prevented most of the well children from joining the parents and ill child on the trip to San Francisco for clinic visits. Frequently, these trips included visits to the park, museums, and the Wharf, which the well children missed out on: "I wished that I could have come along, but I've only gotten to go to the clinic once." The one time this child was included in a trip to the clinic, he had to stay in the waiting room. He viewed it as a worthwhile trip, however, because: "At least I was closer to my mom and dad." Another child talked about not getting to accompany her mother and sister when they went to a nearby town for her sister's therapy: "She'd go with L. to get her shot; then they'd do what L. wanted and she'd buy her stuff. I never get to go with them but sometimes my mom will bring me something."

The well children specifically talked about how the illness interfered with their relationship with the ill child. Their contact with the ill child was minimal when he/she was hospitalized or feeling sick at home. The initial hospitalization following diagnosis was particularly difficult for one child who was too young to visit the hospital: "Since I was too young to go to the hospital, I didn't get to see her for 2 1/2 weeks. I remember being really upset." Five children alluded to the loss of a playmate: "When he was in the hospital, I really missed him. It wasn't fun without him because we used to play together"; "A lot of times I have to leave her alone because she doesn't feel well"; "She can't go outside that much like she used to so there really was no one else to be with"; "When she was in the hospital, there was only one sister left to play with."

Insufficient Social Support. Closely linked to the healthy siblings' decreased involvement in family life was the loss of emotional and social support. With parents frequently gone or occupied by illness-associated responsibilities, the well children lacked family support to help them through the more difficult times: "There was nobody around to talk to really, I just kept most of my feelings inside." One boy longed to be able to stay with his father in their home instead of being sent to his grandmother's during hospitalizations: "I wanted to stay with my dad so he could talk with me and tell me what was going on with D." A reluctance to confront parents was also evident in the siblings' responses: "I felt dumb talking to my mom and dad. They already had enough troubles on their minds. I mean, what else do they need to hear, another trouble?" However, not all children felt they couldn't approach their parents: "My mom was really busy and had a lot on her mind but there was always time to talk to me." In fact, communication channels seemed to widen as the illness progressed. Two-thirds of the families (6/9) were described by the well siblings as eventually capable of talking openly about illness-related issues. Most children identified this open communication as an aid to coping with the illness: "It's important not to hold your feelings in ... It helps so much to let them out and talk to somebody else. We had family discussions and that helped a lot." One precocious 10-year-old child said his family tended to keep their thoughts to themselves so he often initiated discussions because "I thought I should express my feelings." However, two children did not appreciate their family's openness in discussing the illness. One girl felt it was anxiety and guilt-provoking: "I didn't like hearing about it. It

made me feel like I should pay more attention to L." The other child explained his reluctance to talk about the illness: "I just don't feel comfortable, when I talk to them, I think back about all those shots and taking all that nasty medicine. It makes me mad." In fact, recalling the events of the illness was painful for this child, who cried off and on throughout the interview session. Although he was given the option several times to stop the interview, he chose to continue because, "It's good to get it out so I don't have to worry about it."

Parents are not the only source of social support in the family; siblings, too, provide comfort and reassurance for each other. But since the well child's relationship with the sick child was stressed by periods of separation, there were fewer opportunities for emotional and social sibling exchange. During this time of isolation from family members, social support from outside sources was critical. But unfortunately, the camaraderie and emotional interaction typically provided by peers was also lacking. Seven children said the illness seemed to strain their relationships with friends. When they learned of the diagnosis, many of their friends did not know how to respond and, consequently, made themselves scarce: "Some of my friends just seemed to disappear. They didn't call, write or anything." Fear of the illness being contagious was the most frequent reason offered for their friends' abandonment: "One of my friends didn't come around as much, he thought it was contagious. I guess he really wasn't listening when I said it wasn't."

Three children felt that a temporary change in their personalities, brought on by the stress and anxiety they felt at the time of diagnosis, was partially responsible for the alienation of friends: "I was kind of

moping around. I really wasn't myself. We had a nurse come in and talk to my class because people kind of wondered why I was gone so much and why I was acting weird"; "It was hard going to school because I was so upset and people were always asking me questions"; "I could have scared them [friends] away too. I was grouchy and, at first, I didn't like to talk to them about it and answer their questions. Later on, I didn't mind them asking; sometimes I like them to be concerned."

The constant questioning was frustrating for the well siblings for several reasons. As stated before, many of the children initially did not know the answers to the questions, which only seemed to increase their anxiety. Secondly, their peers' concerns focused on the ill child, and their comments continued day after day: "I really didn't like answering all of their questions because I got sick of them"; "Almost all the time I come in at 8:00(a.m.) I hear somebody say, 'How's your sister?' I just don't like hearing it every day. I get bored listening to it"; "Everywhere I go they say 'How's your sister doing?' Nobody ever asks about me."

Also, having to stay with grandparents during hospitalizations interfered with making new or maintaining old friendships: "I couldn't make many new friends because my grandparents didn't let me play outside that much. It was hard because I didn't really have very many friends when I was there." For most children, lack of peer support was only temporary, but it occurred during the first few difficult weeks following the diagnosis when friendship was most needed.

Sibling Emotional Responses

Separation and its consequences evoked feelings of confusion, sadness, loneliness, and anxiety in the well children: "I felt like I was in

this dark world; I was really confused and lonely. There was really no one around to talk to"; "I was really upset and sad because no one really paid attention to me." The diagnosis period was again cited as the time when feelings of alienation were most acute. One younger child said that the hardest part for her at the time of diagnosis was that "They were gone. I always cried. I didn't feel very well." This child, like the other two youngest children, repeatedly used the word "sad" to describe her feelings in response to family isolation. A strong desire for inclusion was evident. When asked what would have helped during this difficult time, a child directly said, "just to be able to come along." A second child explained, "Just going with them makes me feel happy that I'm with them."

Being able to visit the hospital/clinic was seen as beneficial, since it decreased feelings of alienation: "I got to visit just once, but it was kinda fun because it gets lonely down where I was living. It made me feel better because finally I wasn't so far, far away from my family." Visiting also provided the well children with first-hand information about how the ill child was doing: "Once she's away you worry, but when you can see her and you know that she's O.K., that helps"; "It was good for me to go to the hospital and see what she was going through and they [hospital staff] also talked to me about her leukemia."

Two other well siblings (ages 5 and 10 at diagnosis), however, described their visits to the hospital as negative experiences that increased their anxiety. They talked about being fearful of hospital equipment which they knew nothing about: "It was terrible to see her ... She was hooked up to all these machines and I didn't know what they

were." This particular child had been in an unusual situation, as she had visited her sister, who was extremely sick, in the intensive care unit. Another child said he was fearful of his sister's IV: "They brought me in the room and I saw her in bed with an IV in her leg. I just sat by the window and shut my eyes." This child later admitted that his reaction was mainly due to a lack of information: "It scared me because my mom didn't tell me that I couldn't catch it [the disease], and that was important to me." This turned out to be a major concern of five of the children who were anxious about this until they were reassured by their parents or the hospital staff. (Fear of the illness being contagious will be discussed further in the section on the well siblings' responses to therapy).

This general lack of information, involvement and support was extremely anxiety provoking: "I was confused, I didn't know what she had or what was happening. It made me all upset and worried"; "Every day [when she was in the hospital], I was thinking about what she was going through"; "When they go to clinic and I can't come, I just sit around worrying"; "You spend a couple of days worrying until someone finally tells you it's going to be O.K." A lack of contact not only increased the well children's anxiety, but also stirred up guilt feelings: "Not being able to be with her and see her was really hard. I was so afraid that something would happen to her before I got to say 'Hey, I love you.'"

Stress #3: Ill Child's Therapeutic Regimen

The third source of stress on the healthy siblings was the ill child's medical regimen. All of the ill children followed Children's Cancer Study Group (CCSG) research protocols with all the treatments scheduled

at specific times. Treatment consisted of cranial radiation, evaluative procedures and chemotherapy.

Cranial Radiation: The radiation was given on an outpatient basis although several families had to travel far distances to the nearest center with the necessary equipment. Cranial radiation, occurring the second month after diagnosis and lasting 2 weeks, was done prophylactically to prevent central nervous system (CNS) leukemia. As noted in the criteria for subject inclusion in this study, no ill child had ever developed CNS disease. The major side-effects of cranial radiation include skin sensitivity and drying of the scalp, sleepiness (6-8 weeks following treatment, lasting 2-10 days), and temporary hair loss.

Evaluative Procedures: Four procedures are carried out at scheduled intervals to check for the presence of disease and to monitor the child's response to chemotherapy.

A) Complete Blood Count (CBC): A CBC is done to determine the quantity and quality of different types of blood cells in relation to the disease process and the cancer therapy. The blood sampling is usually taken from a "finger stick." The leukemic child has a CBC test at the beginning of each clinic visit because the results influence treatment decisions (the individual CBC values must be at a certain level before the next course of chemotherapy can be safely given). If the child's CBC indicates anemia, thrombocytopenia or neutropenia, hospitalization with supportive therapy may become necessary.

B) Bone Marrow Test: This procedure involves aspirating a sample of bone marrow from the iliac crest (occasionally, other sites are used). The purpose of this procedure is two-fold: It is the conclusive diagnostic

procedure for ALL; it is also another way to evaluate the leukemic child's response to therapy, confirming remission or relapse. The typical schedule for the bone marrow test is on days 1, 14, 28, and 56 of therapy and then every 3 months for 1 year, every 4 months for the next year, and finally, every 6 months for 2 years.

C) Spinal Tap: The spinal tap is also called a lumbar puncture or an LP. A sample of the cerebral spinal fluid, which surrounds the brain and flows down the spinal cord, is examined, initially and periodically throughout the course of therapy, for the presence of leukamia cells that indicate CNS disease. On occasion, an LP may need to be done to rule out CNS infection when the ill child has a fever with no identifiable source of infection. In addition, the LP serves as a route for the administration of anti-cancer drugs (intrathecal/IT) chemotherapy. Since medicines given intravenously and orally do not effectively cross the blood brain barrier, IT chemotherapy is essential in preventing/treating CNS disease. The major side effect of an LP with IT therapy is an occasional headache for one or two hours following the procedure. The typical schedule for the LP is day 1, 14, 28, 35, 42, and 49 of therapy. Half of the ill children had no other spinal taps. The other half (which were randomized to another arm of the protocol) continued to have LPs every 3 months for 3 years, then every 4 months for 1 year, and finally, every 6 months for 1 year.

Chemotherapy: Induction, the first phase of therapy, lasts for 28 days. The ill child receives weekly IV and IT chemotherapy with one medicine given as an intramuscular injection three times a week for three weeks. Prednisone, a corticosteroid, is also given (by mouth/PO)

periodically throughout the course of therapy. Since the child is always hospitalized at the time of diagnosis, part of the induction medicines are given on an inpatient basis; the rest of therapy is given in the outpatient clinic. For convenience, most families arrange for part of the therapy to be given by a local pediatrician.

The intensification phase, which follows induction, centers on prophylactic treatment against CNS disease. The child receives IT chemotherapy (along with radiation—see above) once a week for four weeks. PO chemotherapy is also begun at this time, in the form of pills to be taken daily at home.

The third phase of therapy, maintenance therapy, lasts two or three years depending upon 1) prognostic factors at the time of therapy, 2) the illness' course and 3) the individual protocol to which the child is randomized. During this time, the child continues on the chemotherapy pills at home, gets IV chemotherapy once a month, and comes to the clinic every three months for evaluative procedures (BM, LP and CBC).

The side effects of chemotherapy include nausea and vomiting with anorexia, bone marrow suppression, and temporary hair loss. The side effects associated with prednisone are an increased appetite with weight gain (especially in the face and abdomen), moodiness, and gastrointestinal upset. All of these side effects subside once the medicine is stopped.

The therapeutic regimen with its use of needles, uncomfortable positioning, varied side effects and interruption of normal routines, is feared and dreaded by most children with cancer. Although the frequency of the procedures usually results in an improved tolerance

(especially for the older children), the experiences are still painful and anxiety-producing for the ill children and their families. During the interviews, the well siblings alluded to three major distressing consequences of the therapeutic regimen: 1) witnessing physical and personality changes in the ill child; 2) witnessing the ill child's anxiety and fear of the procedures; and 3) adjusting to changes in the family's usual routine.

Witnessing Physical and Personality Changes. The most dramatic physical change the well children talked about was the ill child's hair loss: "At first, I was really shocked! One morning she woke up with all this hair all over her pillow. She knew it would probably fall out, but I just thought it wouldn't"; "She lost a lot of hair and she looked different; She looked like a stranger - her face looked the same but her hair got pretty different to me." The well children were also exposed to frequent teasing of the ill child by strangers as well as peers: "People would say stuff like 'he looks ugly' or 'he looks stupid' but I didn't believe what they were saying"; "She wore a scarf but people would say stuff. I'd just tell them she has leukemia - and the look on their faces, I mean they'd just turn white."

Change in their siblings' body weight was also upsetting to the well subjects. One child vividly recalled finally being able to see her sister again after two and one half weeks of hospitalization: "The first time I got to see her, I had to look through the window to her room. I just got sick. I mean she looked blah - all scrawny and stuff." Another well child was placed in a frustrating position when her twin sister gained weight on prednisone: "It's hard; L. always says 'you're so skinny, I'm so

fat.' It makes me upset and feel so bad that I just want to cry." The healthy children were also aware of the more subtle physical changes, such as lethargy and proneness to bruising (thrombocytopenia) which often interfered with sibling play.

While on prednisone, the ill child underwent a personality change that was apparent to each of the well siblings: "When she was on prednisone she was just a total grouch. You didn't want to mess with her"; "It [prednisone] made L. so irritable that it was hard to get along with her"; "She used to be grouchy all the time and didn't appreciate when you'd try to help. I guess it was from the medicines. Her moods would change really easily."

Witnessing the Ill Child's Anxiety and Pain. Throughout their interviews, the subjects seemed preoccupied and disturbed as they recalled the ill child's anxiety and pain in response to therapy. The younger children seemed more preoccupied by "needles" and "IV shots": "I felt sorry for her because she had to get those painful needles stuck in her." Several children who had been to the clinic talked about their experiences: "It was hard looking at your sister and seeing her get that big old needle in her back"; "I heard her screaming from the bone marrow. It made me want to go in and tell the doctors to stop but I couldn't."

The older children reacted not so much to the fear of "needles" and "shots", but spoke more of the difficulty of witnessing pain: "Seeing her go through the pain or knowing that she's going through it, that's the worst." Two other children agreed with this statement, identifying that witnessing the ill child's anxiety and pain was one of the most

frightening and disturbing aspects of the illness. In addition, the well siblings tended to take on whatever attitude the ill child displayed toward treatment: "He would get really scared about going to the clinic and I got scared too"; "I always ask her if she's scared. If she's not worried, then I don't worry."

Changes in Family Routines. This third consequence of the therapeutic regimen was as pervasive and stressful as the other two. The ill child's hospitalization frequently meant that the well sibling stayed at friends' or grandparent's homes, facing altered family structure and routines: "When my parents and C. had to go somewhere, I'd think, 'Oh no, not again.' It meant that I had to stay at my Grandparent's with nothing to do"; "When R.'s in the hospital and my mom's gone, the whole routine at our house changes." The children who stayed home when parents were at the hospital or clinic assumed new roles and responsibilities: "We usually help my mom cook dinner and stuff but when she was gone we were doing everything. We all just took our share of the chores and got them done"; "I had to help with the chores and clean the house." Both of these statements came from adolescents who coped with their new responsibilities by rationalizing that although it was hard, "you just want to help as much as you can"; "I knew I was doing it for my mom."

Five children talked about how giving medication at home (oral chemotherapy) became an important aspect of the daily routine: "We had a lot of new medicine around the house. We kept a calendar out in the kitchen to see what dates to give A. the pills"; "L. had to take a lot of pills at home. If she wanted to go somewhere I'd always remind her

to take them. She really didn't like taking pills and she always tried to make everyone forget so she wouldn't have to take them"; "H. hated to take her pills. She had a hard time swallowing them so it always took awhile of us coaxing her before she'd do it."

As a result of the illness and the therapeutic regimen, changes in family social activity affected the well children. Their comments revealed feelings of isolation and self-sacrifice: "My family stopped doing things they mostly do. We just stayed home a lot"; "I guess it really changed the whole summer. We didn't do much of anything or go on vacation. We were just kind of shut-up together"; "There was a parade with all the halloween people and I didn't get to go because P. was sick and no one could take me"; "No one asked for anything that Christmas; my parents had enough on their minds." These feelings were most acute during the first several months of the illness: "It's really different in the beginning. Everything that happens [means] you have to give up a lot, but after awhile it gets back to normal. Sometimes you think it's never going to, but it does."

The well children did not elaborate on their families' reactions to their feelings of isolation. The author suggests that parents could not adequately attend to their well children's needs for the following reasons: 1) shock and heightened anxiety at the time of diagnosis; 2) enormous amounts of time and energy invested in the ill child's care; and 3) fear of the ill child getting sick due to the immunosuppressive side effects of therapy. The basis for this last factor, an increased susceptibility to infection, was also the primary reason for isolation among family members: "If I'm sick, we have to be in separate rooms

or sometimes I'd have to go down to my grandpa's so H. wouldn't get sick on top of her leukemia"; "The thing that's really difficult for me is when I got a fever, I had to stay in my room for like four or five days. I mostly saw my dad because he came in my room to eat dinner with me. When my sister was taking a nap or went to sleep for the night, I would come out but I couldn't come out any other time."

Because parents were worried about a superimposed illness/infection, they often restricted playmate contact and large group activities. The rules were especially strict when the WBC was low: "I can't play around people who have a cold because I could bring it back to D."; "When her 'counts' were low, nobody could come over"; "When she had 'low counts', we couldn't have any friends over and I couldn't really see her that much. I had to be sterile to talk to her." Two children mentioned that going to the movies, where there would be a large crowd in close proximity, was worrisome to parents and, therefore, was often discouraged or even restricted. One well child remembers not being able to go to her girlfriends' slumber parties for the first several months after her ill sister's diagnosis: "When L. was first diagnosed, I was invited to seven slumber parties and I couldn't go. Mom was afraid I might come back with chicken pox or a cold."

Sibling Emotional Responses

Although the therapeutic regimen is focused on the ill child, the consequences also had a significant impact on the healthy siblings. To begin with, they were subjected to the cycles of lethargy, hair loss, bruising and irritability which the ill child experienced throughout the course of therapy. These physical and personality changes in the ill

child were extremely frightening to the healthy siblings as they confirmed the reality of the illness and its threat to the ill child's life. One 10-year-old boy recalled how he felt when his sister lost her hair: "I felt like a stranger to her. I felt kind of scared for her, that she might die." In general, the well children gauged the ill children's status by their physical and personality characteristics: "She was all tired and hurting, and really cranky too. She wasn't doing good at all."

Three children admitted to feeling embarrassed about the physical changes which occurred in the ill child. Their reactions, closely aligned to anger, seemed to be prompted by insensitive teasing: "Their [school-mates] teasing made me really mad. I mean if they couldn't accept that [hair loss], then they should just stay in their house or something"; "People looked a lot. I was embarrassed but not that much. I tried not to think about it."

Talking about the physical and personality changes, as well as witnessing the ill child's anxiety and pain over procedures, made the well children contemplate their own illness vulnerability: "When I see her cry, when she's having trouble trying to control, when she's really in pain, I feel 'oh boy, I'm glad I'm me"; "It was important for me to know I couldn't catch it"; "I was scared if I got it, I would have to go through all the same things."

Although the well siblings acknowledged that the personality changes were influenced by the medicines, they still expressed anger and frustration at the ill child's behavior: "I'd get mad because she would pick fights with me and I'd get in trouble." The same child coped with

the situation by trying "not to get involved" and attempting "to understand she was going through a lot." A second child also used avoidance (withdrawal) as a way of coping with her sister's irritability: "I got mad at her before I knew it was the medicines, but now I just go into my room." One adolescent sister was especially articulate about her feelings toward her younger sister: "She wasn't very happy. She was bratty and moody and argued a lot. I was wondering if she was going to get back to her normal self because I knew she had changed. I didn't like it. I didn't want her to be that way. I was kind of mad and I just couldn't wait until she was off the prednisone." This teen was also able to recognize that her sister's negative behavior was, in part, due to "being mad at what was happening to her, too" and that "it was, at first, hard for R. to accept what was going on."

These ambivalent feelings of anger and frustration, on the one hand, and compassion and empathy on the other, sometimes led to guilt. A 7-year-old sister explained that her brother's moodiness, although she knew it was caused by the medicines, provoked her to fight with him and even hit him; and after the fight, she spoke of "not feeling very good because he's my brother."

Guilt feelings surfaced in several contexts throughout the interviews. As described in a previous section, the well children felt guilty for being jealous, angry, mean to the ill child and even healthy themselves; yet at times this guilt was displaced by relief at being healthy and not having to undergo painful procedures and physical changes. A third guilt response was associated with protecting the immunosuppressed leukemic child from catching a complicating secondary illness: "We were all

worried if D. caught it, she might die. Then it would be on your conscience because you got sick and gave it to her."

Each of the healthy siblings was strongly influenced by the ill child's anxiety and pain. Hearing about or watching the ill child undergo painful procedures was frightening. The younger children seemed particularly preoccupied with the "nasty needles", "big old needles" and "bone marrow shots." A sense of helplessness pervaded their fear. One healthy child told how he had asked his parents, "Why do they have to do all of those tests?" Another well sister said, "I didn't like to hear her cry and it just really hurt me a lot to hear her in the room screaming. I felt so bad. I wanted to do something, but there was nothing I could do."

Disappointment and resentment were evident in the well children's comments about the changes in family routines. At times, the family's and the well child's social activities were restricted. The healthy siblings reported that isolation "wasn't very good", "it wasn't fun" and that they "didn't like it." A 7-year-old sister talked about how hard it was for her to be without her mother's support when she was sick (she had to go to her grandparents' for the duration of her illness): "My mom wasn't there when I was sick; I never got to see her."

The family changes described by the well children were often overwhelming, especially for the first few months following the diagnosis. The emotional climate in the home was determined by the illness: "When my mom worried, that would worry us [well children] a lot. R. really was the only thing on everyone's mind and you, yourself, were like that. But that finally wears off, like everything else." This was the same child who spoke of the overpowering sense of futility she initially felt when thinking that family life would never return to normal.

Positive Aspects

The leukemic illness did not provoke exclusively negative consequences for the well siblings. The same experiences that engendered feelings of isolation, frustration, anger, anxiety, resentment, fear and rejection, also brought about positive and adaptive responses in the healthy siblings and their families.

Increased Sensitivity and Empathy

As the healthy children talked of the ill child's anxiety, pain and self-consciousness, they expressed feelings of empathy and love: "It makes me feel sorry for her because when she's sick, it's not like her. She just lays there"; "I feel sorry for her when she has to get those painful needles stuck in her. I really feel sad for her"; "It's hard looking at your sister and seeing her get that big needle in her back." A 15-year-old adolescent sister sensitively described her feelings of sorrow and helplessness: "I felt sorry for her because of all the pain that she was going through. When you think about it, all those needles she gets (pause) ... I try to put myself in her position. You have to go through it, you have no choice. But still, it must hurt a lot. Seeing R. go through it, that's the worst; because you just don't want anybody you love having to go through anything like that."

The healthy siblings also expressed a desire to protect the ill child from the ridicule of peers and strangers: "I try to stop them from saying mean things. I tell them she has this very dangerous disease that makes her lose her hair, so please don't tease her like that." Another child would quickly rebut the cruel remarks by demanding "Just be quiet! He

is sick!" A third child explained her protective role at school: "We're at the same school and I was in the biggest grade. So if anybody said anything, I'd get on their case." Of the four children who adopted a protective role, three were older siblings and one was a twin.

A twin sibling relationship is unique in itself, let alone within the context of a cancer illness. The 12-year-old twin in this study quite poignantly described trying to protect her sister from social discomfort and self-consciousness. She explained that her sister wore a wig because she did not want anyone to know she had lost her hair. But keeping this fact a secret became difficult, especially when they went to the amusement park and rode on the roller coaster: "L. always had to put her hand on top of her head to hold the wig in place. She feels kind of funny doing it because people may think it looks weird and wonder why she's doing it. So, I do the same thing because I think it makes her feel better."

Even at home, the well twin was very sensitive to her sister's hair loss: "I think how hard it must be to have no hair. I try not to bring anything up about my hair, like it won't curl right because I know it upsets L. I even let her curl and comb my hair since she doesn't have any. This same child tried to be supportive about other physical changes her twin had experienced: "She always says 'you're so skinny, I'm so fat.' I just want to gain weight or help her lose weight. I try not to eat stuff that's fattening ... A lot of times she isn't good at things like playing soccer or jumping rope. She used to be better than me before she got sick but now it's not that way. It's hard because she thinks she can't do anything and she'll say it to me. It makes me feel like I want

to do worse than her so she'll do better than me."

The healthy siblings were also aware of the illness' impact on their parents. They spoke of not wanting to "ask for anything special for Christmas" and not complaining to parents because they "didn't want to put any more pressures on them." As one child said, "They already had enough troubles on their minds."

Personal Maturation

Several of the healthy siblings spoke of the sudden maturity prompted in them by the cancer illness. Two children (16 and 10 years old) talked about how the illness experience helped them to "grow-up a lot," to become more tolerant of others and to develop inner strength. Another teen explained that she and her family now "have a better attitude toward things. In the beginning we were all kind of negative, but now we are more positive about bad things." This same teen spoke of a second personal change: "I kind of have a new perspective on life. It helped me see how lucky I am that I don't have this and to also value time more."

Increase In Family Cohesion

Three children said that the illness had brought their family closer together: "Everyone's a lot more willing to do and care for each other. Like we are able to talk openly together and say 'I love you'"; "We are just closer now and can have open family discussions." One of these three who described his family as "closer" said that his father, in particular, had begun to communicate more easily and openly with other family members.

Among the positive results described by the well siblings, most were voiced by the three oldest children. However, two younger children also

spoke of positive changes/good things that had come from the cancer experience. One 10-year-old said that he had grown-up a lot during the 3 1/2-years since his sister was diagnosed. The other child (7 years old) reported that his father now "hugs me a little more." This seemed to be his way of saying that he and his father shared a closer relationship as a result of his sibling's illness.

Overall, the cancer experience put the well children face to face with a life and death issue. By sensitizing them to the feelings of other family members, the illness helped them to become less self-centered and more appreciative. A 16-year-old teen summed up her most important gain from her sister's illness: "It opens up your eyes to know that something like this can happen to your family. You never think it could happen, but things do. You really never know what can happen, so you should take what you have today and care for it."

What Has/Would Have Helped

When the healthy siblings were asked what has/would have helped make the illness experience easier for them their responses centered around six main categories: 1) more frequent hospital/clinic visits; 2) more information about the disease and its treatment; 3) open and honest communication; 4) sibling involvement; 5) at-home care during sibling's hospitalizations and 6) passage of time. Each category will be discussed within the context of the well childrens' comments and suggestions.

More Frequent Hospital/Clinic Visits

Not being able to visit the hospital and see the ill child was very frustrating for the well children: "I was too young [to visit] and I didn't

get to see her for two and a half weeks. But I wish that I could have. That would have helped a lot"; "I had to sit in the lobby most of the time. There was nothing to do and I was bored." Another child explained he got to visit only once but it was a good experience: "It was kind of fun, because it gets lonely down where I was living." Being able to visit with the ill child in the hospital was also reassuring: "When she's away you're worrying, but when you can see her and know that she's OK, that helps."

Visiting the clinic was viewed as helpful for several reasons. A teenage sibling felt the clinic had a friendly and positive atmosphere: "It's different from being in the hospital. It seems like everybody's fine and they're just coming to get a little check-up or something. It's not like something is really wrong with them." Coming to the clinic was a means of gaining direct information about the treatment center and the procedures: "It helped me find out what she was going through by going to the clinic." Being included more often in clinic trips to San Francisco could have helped to decrease a sense of isolation/exclusion: "I wish I could have come along with them more when they went to the clinic. I've only been there once."

More Information

Learning about the illness, its treatment and the ill child's prognosis was useful for the healthy siblings as it helped decrease their anxiety and fear: "I always wanted to learn as much as I could. I read through that book [You and Leukemia]¹ many times. Reading as much as you can about it, that really helps." Receiving information at the time of

¹Baker, L. You and leukemia: A day at a time (Rev. ed.). Philadelphia: W.B. Saunders Company, 1978.

diagnosis was important to these children: "My mom was the first to know about it. I wanted to know what it was and she told me"; "It was kind of scary with his getting all those medicines. I didn't know what was going on at first until they told me." One of the first things that many siblings feared and wanted to know more about was the possibility of the ill child's death: "That's what's so hard at first until you finally get so relieved that someone explains everything to you and that you finally know ... that it's going to be alright."

Because gaining first hand information is important to the siblings of ill children, a special "sibling program" was held at the clinic during summer vacation. The purpose of the program was two-fold: 1) to educate them about cancer and its treatment, and 2) to provide them with the opportunity to share common concerns and feelings associated with being the "well child." The four children who attended the program felt it was very beneficial, especially learning about the procedures.

Open and Honest Communication

Open and honest communication was important not only in regard to information about the disease and therapy but also in terms of how family members were affected by the illness: "I talked to my mom and dad about it. We had family discussions and that really helped a lot"; "Sometimes I think about my sister's leukemia and I don't understand something. Then I ask them [parents] what it means cause I couldn't understand and they tell me." Talking to grandparents, well brothers and sisters, and friends was also helpful: "I talk to my friend Tiffany. Her family doesn't have any problems but she can really help me a lot when I'm upset." Four children specifically said that talking about their "feelings" helped: "I think I should express my feelings"; "I used to want

to keep my feelings inside but now I've changed my mind"; "Just talk about your feelings, don't hold them in no matter how old you are or who you are. It helps so much to let it out and talk to somebody else."

Not all of the well children agreed it was always helpful to talk about the illness or their feelings. Two children said it upset them too much and that they did not want to dwell on the illness. The child who cried throughout his interview was one of the children who did not like to talk about his sister's illness; yet he turned down the chance to terminate the session because "It's good to get it out so I don't have to worry about it." Perhaps this suggests the desire to choose when and what to communicate rather than a desire not to talk about the illness at all.

Sibling Involvement

Sibling involvement actually encompasses the three other categories - visiting the hospital/clinic, being able to talk openly and honestly about the illness and therapy, and getting more illness-related information - all of which helped the well children feel like active family participants. But equally important was the chance to participate in the ill child's care, especially when he/she was not feeling well: "At first she was kind of tired. She just wanted to lay down and be in bed so I'd get her whatever she wanted me to. If I could help her, if there was anything I could do, then I'd do it. That helped me feel better"; "We'd play cards or a game. I'd get her things like a drink of water. It was hard not to baby her because you wanted to help her so much." Helping the ill child included watching out for him/her during playtime: "Like if he falls, I help him up and if he hurts himself I take him into the house. I like things like that."

At-Home Care During Sibling's Hospitalizations

Two children repeatedly stressed how much they would have preferred to be allowed to stay in their own homes during hospitalizations. One child (11 years old) explained that the shuttling back and forth from his home in the afternoon to his grandmother's house in the evening got "confusing and mixed-up": "It didn't make sense. I could have stayed here and the nights my dad had to go to San Francisco, then he could drop me off at my grandmother's house. Then I could be around my dad and he could tell me what's happening with D." The other child, who was younger (7 years old) spoke of missing the security of his familiar home environment: "It wasn't very fun [being at his grandparent's house] cause I forgot my best bear and I didn't have all of my toys to play with and I got homesick."

Passage of Time

The last factor, which helps in many crisis situations is one that neither well siblings, parents, nor health professionals have any control over: the passage of time. With time, things settled down although in many cases, they have still not returned to normal: "Lots of times I even forget she has it. Like now, it doesn't even phase me. The only thing that's different is the treatment she has to get and what you go through at first, but now it's pretty much the same"; "It is all so different at the beginning. Everything that happens, and you have to give up a lot but after awhile it all pretty much gets back to normal."

Advice to Other Healthy Siblings

Each child was asked the question, "If you were trying to help another brother or sister of a child who was just diagnosed with

leukemia, what kind of things would you tell them to expect to happen in their family?" The purpose of this question was to elicit what the well child singled out as something important to pass along to a child in a similar situation. The younger children were very direct in their responses: "It would be scary and that you'll get worried"; "You'll probably be sad"; "Well, I would say if he gets sick, he would have to stay in a room and not be able to come out"; "He might have to see his sister with needles"; "I would say just expect her to go to the hospital a lot and she will get more attention than you"; "You would have to stay away from your parents and sister a lot and you might be sad and lonely, but it would be worth saving a life"; "Your parents will be partial to the other kid and it seems like they don't care and forget about you, but try not to think they love the other kid more." The three older children were more positive and analytical in their responses: "Well, everybody will be pretty negative, but don't think the worst. You know, the doctors may whisper and stuff. But you gotta keep thinking that the worst that can happen is that they'll die and if they do, they'll be in peace. But they'll probably make it through because of all the treatments and stuff"; "Just talk about your feelings, don't hold them in ... it helps so much to let it out and to talk to somebody else"; "Things all get back to normal. That's the one thing I'd like to tell another brother or sister because you think it's never going to, but it does."

CHAPTER V

SUMMARY

Conclusions

The stresses of living with a brother or sister who has leukemia had a significant impact on the healthy siblings in this study. The well children's statements clearly reflected the magnitude of the deprivation and social isolation they felt: "It was like people forgot about me"; "Most everything is going to change"; "Expect not to be cared for a lot of the time"; "Like once in awhile I think, 'Why us, we're so different.'" One teenager, when asked about the worst part of having a sister with leukemia, could not specify any one aspect; instead, she replied, "The worst thing? Probably just the trauma of the whole thing, knowing that you might lose your sister, and people treat her differently and they treat me differently, too. [pause] I guess they treated our whole family, all of us, differently."

The first couple of months following the diagnosis were described as the hardest time which brought about the most changes and required the most self-sacrifice from the well children. However, subsequent crisis periods (when the ill child developed complications and was frequently hospitalized) reinstated an atmosphere of uncertainty and family disruption. Several children, whose brother or sister had just finished or was about to finish therapy, talked about family life beginning to return to "normal." Yet, they still spoke of themselves and

their parents worrying about the future well-being of the leukemic child. In addition, two well children, even 5 1/2 and 4 years after the illness experience, continued to feel the remnants of its effects: "It [parents favoring the formerly ill child] still happens. My mother doesn't want to admit it, but I know it does. I accept the fact. Most parents will do that. It just makes me pretty mad because N. needs a chance to be treated like a normal person."

When viewed collectively, each aspect and phase of the illness represents an emotionally overwhelming and stressful experience for the healthy siblings. They experienced a great deal of disruption in their lives as a result of the changes brought about by their brother or sister having leukemia; and they had to deal with these changes in the face of much uncertainty and a lack of emotional support. The strongest and most poignant concluding statement came from a 10-year-old brother of a child who was diagnosed 3 1/2 years ago: "I felt kind of mad that she was getting this disease and she's wrecking - well not really she is but the disease is getting me upset, mad, and confused. It was wrecking my life, like taking it away. But now, she's getting better and we are starting over again. It's like we have a new life." Just as this child's bitter statement ended on a note of optimism, the same experiences that threatened the well children's healthy adaptation were also growth-producing. The illness increased the well siblings' capacity for empathy, enhanced their personal maturation, and promoted family cohesion. As one child explained, "It [the illness experience] is really not all bad." The older children were better able to recognize and describe the subtle positive consequences of the illness. Perhaps with time the younger

siblings will also be able to draw such conclusions.

It was encouraging that the positive effects identified by this study agreed with findings from other studies (Ises, 1979; Taylor, 1980; Sourkes, 1981). The impact of the illness was not viewed exclusively as a negative experience, as it provided opportunities for individual and family growth. However, it would be naive to think that the coping process develops smoothly and painlessly, with no risk of maladaptation for the healthy siblings and their families. As the well siblings in this study indicated, there were several key variables which facilitated their adaptation and coping.

Limitations

The small sample size and the lack of random selection of subjects are the two factors which limit the external validity of the study and, therefore, its generalizability. The inability to control for the sex, ethnicity and birth order of both the ill child and well sibling further restricts the analysis of the data and its generalizability. Although the minimum length of time since diagnosis was controlled, the upper limit, in several cases, was more than 3 1/2 years which certainly may interfere with the healthy siblings' recall ability (due to a time lapse and/or a young age). In fact, two of the younger children (ages 3 and 3 1/2 at the time of diagnosis) had a difficult time answering interview questions, frequently saying "I don't know" or "I can't remember." Another important factor may have interfered with the accuracy and/or completeness of the data: The information shared by the healthy siblings,

during a single interview session, reflects only what they were comfortable in talking about with the interviewer, whom in most cases (8 of 11) they had not previously met.

Despite limitations, this study is important in that its findings correlate with those of previous studies (Gogan, Koocher et al., 1977, Peck, 1979; Cairns et al., 1979; Iles, 1979, Taylor, 1980; Sourkes, 1981; & Spinetta, 1981). Thus, the validity of its findings and their potential usefulness to nursing practice are strengthened.

Implications For Nursing

Given the limitations of this study, it is evident that further research and collaborative efforts must occur before definitive guidelines for nursing practice can be established. Yet, the positive and negative effects deduced from the healthy siblings' responses can give direction to the nursing practice of pediatric cancer patients and their families.

To begin with, nurses (as well as other health care professionals) need to become more aware of the various ways a pediatric cancer illness can affect the healthy siblings. This knowledge can then be applied to each family the nurse works with so that a complete family assessment can be made. But getting information about the well children and how they are coping is often difficult. Siblings are not often in the hospital and clinic settings, leaving minimal opportunity for interaction with the nursing staff. Also, parents overwhelmed by the illness experience, may not volunteer information about the healthy

siblings or even realize that these children have problems related to the illness. Therefore, it is important that nurses inquire about the other children at home. Patient/family education should include anticipatory guidance concerning the healthy sibling's role in the illness experience; parents should be strongly encouraged to attend to the unique concerns and feelings of their well children.

From the onset of the diagnosis, health care professionals must be open and honest with pediatric cancer patients and their families, advocating the same type of communication at home. Every effort should be made to have the healthy siblings attend the initial family conferences with the pediatric oncology team, where much teaching and emotional support occurs. Parents may need help in breaking the news of the diagnosis to the well children as well as in explaining the specific disease and its therapy. Perhaps a special teaching session for the well children can be arranged during the evening or weekend hours. Important points, such as 1) cancer is not contagious, 2) you cannot wish or make someone else get cancer, and 3) fear of the ill child's death, must be addressed as soon as possible after the diagnosis.

Involving siblings in the care of the ill child can help decrease the well children's sense of isolation, loneliness and anxiety. Frequent hospital visits also allow them to see both the ill child and parents, while gaining first-hand information about the disease and its treatment. The primary nurse should make every effort to work around visiting restrictions, as sibling contact in the hospital is critical for both the well and ill child. If distance and/or unyielding hospital rules interfere with visitation, then letter writing, phone calls, or picture exchanges can act

as substitutes. If part of the cancer therapy is done on an out-patient basis, then the well child should be allowed to accompany the ill sibling to see another side of therapy and dispel any disproportionate fears about procedures. Also, interactions such as playing games, holding hands, or helping the ill child eat when hospitalized or feeling sick, should be encouraged to alleviate feelings of helplessness.

Educational and support group programs are other ways to involve, educate, and provide the chance for healthy siblings to express the unique concerns and feelings associated with being the well brother or sister of a child with cancer. Frightening procedures, such as bone marrows and lumbar punctures, can be explained through slide show presentations - a distancing technique which makes the information less threatening. Puppet play participation may also facilitate learning among children (especially pre-school and school-age) while reducing their fears over anxiety-provoking issues. Perhaps the most beneficial aspect of forming a group of healthy siblings who are in a similar situation is the camaraderie which develops as they share common fears, feelings and frustrations.

Individual teaching and emotional support can occur on more of a spontaneous basis with the primary nurse, who has come to know and establish a trusting relationship with the family. A "sibling network" is another personalized way the well children can be helped in the adjustment and coping process. Having a well child who has "been through it all" share information and advice can be comforting and reassuring.

Productive and positive experiences in school and peer relationships are important in fostering the normal growth and development of the healthy siblings. But the well children's responses revealed that the stresses arising from the illness can interfere with school and strain friendships. This additional burden can be eased by having a nurse visit the well child's class to talk about the illness and how it affects the whole family, answer questions, and provide suggestions for supporting their classmate. As the child in this study explained, she was relieved once the nurse spoke with her classmates because it helped them understand why "she was acting so weird."

It is important to remember that well children may be reluctant to "complain" or "burden" parents with their problems. Also, the cancer illness is likely to interfere with the parental attention formerly given to the well siblings. Therefore, parents should not be expected to provide the sole means of sibling support. Information and emotional support should be made available from outside sources. Nurses can be instrumental by soliciting the aid of extended family members, close friends, school personnel, other cancer families and the health care team.

Family-centered care necessitates an understanding of how a pediatric cancer illness affects each member of the family. Thus, nurses must continue to be committed to research which seeks to validate and build upon the study's findings. Optimally, research should be aimed at the family as a unit, identifying the impact of the illness on each member. If parents are having difficulty accepting the diagnosis and coping with the demands of the child's illness and therapy, it seems

reasonable to expect that the sibling, too, will experience increased stress and inadequate support for maintaining healthy adaptation and coping behaviors.

Recommendations For Future Research

The following recommendations for further studies are suggested:

1. Replicate this study with a larger sample size while controlling for birth order to determine the role that placement within the family constellation may have.
2. Replicate this study with a larger sample size while using supplemental data collection tools, such as behavioral checklists, self-concept scales, and level of anxiety indices.
3. Replicate this study using a larger sample size divided into three age groups (pre-school, school-age, and adolescence) to compare and contrast age-specific responses/concerns.
4. Study the impact of various pediatric cancers on matched pairs of healthy siblings to determine possible differences that are disease-specific.
5. Conduct a longitudinal study, interviewing siblings at fixed points throughout the illness/treatment course to determine the pace and evolution of consequences.
6. Conduct studies evaluating how the healthy sibling's adaptation and coping processes are influenced by 1) family communication styles, 2) amount of information conveyed to the siblings about the disease and its treatment, 3) sibling involvement, and 4) social support systems.

7. Collaborate with nurse/health care researchers involved in parallel studies to develop and standardize the tools used to identify the impact of a pediatric cancer illness on individual family members and the family as a unit.

APPENDIX A

INTRODUCTORY LETTER



SCHOOL OF MEDICINE
DEPARTMENT OF PEDIATRICS

SAN FRANCISCO, CALIFORNIA 94143

Department of Pediatric Oncology
University of California Medical Center
San Francisco, California 94143

Dear

We on the oncology team are continually trying to identify the special needs of our patients and their families. One area of concern is to try to better understand the impact of a cancer illness on healthy siblings. Robin Kramer, a graduate nursing student who has been working with us in the clinic, is going to be doing a study on "Living with Childhood Cancer-Impact on the Healthy Siblings." Because of our concerns in this area, we have agreed to work with her on this research project which will help identify the needs of healthy siblings and how they can best be met.

During a recent telephone conversation with Rita Fahrner you gave permission to be approached as a potential participant; thus, we have made your name available to Robin Kramer. Your decision to participate in the study is on a voluntary basis. Your agreement or refusal will have no bearing on the treatment or care your child will receive. Enclosed you will find copies of the permission and assent forms which will provide you with more information about the study. Robin Kramer will be meeting with you at your next clinic visit to answer any further questions and to sign the permission/assent forms if you should decide to participate. The interview session can take place the same day or on another mutually convenient date.

Sincerely,

A handwritten signature in black ink that reads "Arthur R. Ablin MD".

Arthur R. Ablin, M.D.

APPENDIX B
PERMISSION/CONSENT FORM
(Parent)

Study of Living with Childhood Cancer-Impact on the Healthy Siblings

1. Robin Kramer, a graduate nursing student at the University of California, San Francisco, is conducting a research study to learn how siblings of leukemic children perceive and interpret the impact of the illness experience on their lives.
2. I agree to have Mrs. Kramer interview my child _____ for approximately one hour at either the pediatric oncology clinic or in my home, depending on convenience. A copy of the general questions are available upon request.
3. I also agree to have Mrs. Kramer briefly interview me for 15 minutes after my child's interview.
4. Every effort will be made to preserve confidentiality of the information the investigator may gain from both of the interviews. My child's responses will not be shared with me unless he/she has given permission to do so.
5. The research conducted by Mrs. Kramer may result in health professionals' improved understanding of the needs of pediatric leukemic patients' siblings and the ways of better supporting their coping and adaptive responses. The interview may also be therapeutic for my child as it will single him/her out as an important member of the family while allowing a chance to vent feelings and concerns. I am aware that the interview may involve some discomfort for me and my child as we will be sharing personal feelings about the illness experience.
6. I may decline to enter this study or withdraw from it at any time without jeopardizing my leukemic child's treatment.
7. If I have any questions or concerns about the research study I can contact Mrs. Kramer at (415) 564-1467.
8. My child and I will not receive any compensation for our participation.
9. I have been given a copy of this permission form to keep.

Date

Parent/Guardian signature

APPENDIX C
ASSENT FORM
(Child)

Study of Living with Childhood Cancer - Impact on the Healthy Siblings

My name is Robin Kramer, and I am a graduate nursing student at University of California, San Francisco. I would like to talk to you about what it is like to live with a brother or sister who has leukemia. What you have to say is very important as it will help other nurses, doctors, psychologists, and social workers better understand how an illness, like leukemia, changes the healthy brother's and sister's lives. Your answers will be used in trying to help other children like yourself who have a sick brother or sister.

You do not have to talk with me if you don't want to. It is up to you to decide, and your decision will not affect you or your parents, or your sick brother or sister.

If you decide to talk with me I will talk with you for 1 hour about the ways in which your life has changed since your brother or sister became ill with leukemia. I would like to use a tape recorder so I don't miss any of the important things you say. We can play with the tape recorder before we start to talk so you know how it works. If you don't like a question or it makes you feel uncomfortable, you don't have to answer it. If during our discussion you decide you don't feel like talking any more, that's OK and we will stop.

What we talk about will be a secret between you and me. I will not tell anyone about the things we talk about. I will not tell your parents what you say unless you tell me to.

I will be talking with you at the clinic or in your home, which ever works best. You can also have a copy of this form.

By signing my name below, I have agreed to talk with Robin Kramer and help her with this study project.

Name _____

Date _____

APPENDIX D

PARENT QUESTIONNAIRE
AND
INTERVIEW GUIDE

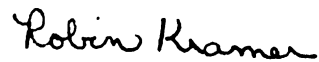
Explanatory Letter for Parental Questionnaire

Dear

Attached is a demographic data and family background questionnaire which should take about fifteen minutes to fill out. This information is an important part of the study and will be used in analyzing the sibling interviews. You have the right to inquire about the necessity of any question and can talk with the researcher after your child's interview. Consent for participation will be implied by your completion of the form.

Thank you for your cooperation.

Sincerely,



Robin Kramer

The next section of questions pertain to family members. Please indicate the name, sex, birthdate, and age at diagnosis for each of the leukemic child's siblings. In column 5 note whether the sibling has lived at home since the child with leukemia was diagnosed. In column 6 describe the health of each child noting any medical problems, serious illnesses, diseases, injuries, or accidents. Provide information on each child; if there are no health problems specify "healthy".

<u>Name</u>	<u>Sex</u>	<u>Birthdate</u>	<u>Age at diagnosis of the leukemic child</u>	<u>Has lived at home(yes/no)</u>	<u>Health Status</u>
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____

Please indicate whether you or your spouse have had any medical problems, serious illnesses, diseases, injuries, or accidents since your child was diagnosed with leukemia. Provide information for each parent; if there has been no health problem specify "healthy".

Mother's health _____
 Father's health _____

Does anyone else live in your home with you? If yes, specify name, age, and relationship.

PARENT QUESTIONNAIRE

1. Mother's name _____ Birthdate _____ Occupation _____
2. Father's name _____ Birthdate _____ Occupation _____
3. Marital Status _____
4. Mother's highest level of education completed _____
5. Father's highest level of education completed _____
6. Leukemic child's name _____ Birthdate _____
7. Month and Year of Diagnosis _____
8. How many times has your child been hospitalized because of his/her leukemia?
Please approximate the length of stay (number of days) for each hospitalization.
9. Who cared for the other children when you were tied up at the hospital (name and relationship)?
10. Was the care provided in your home or did the siblings need to go to the homes of others?
11. How often did you get to see the other children during periods of hospitalization?
12. Who cares for the other children when your child has to go to the oncology clinic?
13. Do you live far enough away from the oncology clinic that you need to be gone overnight?

PARENT INTERVIEW GUIDE

- Has there been any serious illness or death in your extended family (grandparents, aunts, uncles, cousins) since your child was diagnosed with leukemia?

- Has any other type of crisis ever occurred in your family since your child was diagnosed with leukemia? If yes, please explain the situation.

- Do you remember any behavior changes with the siblings before the illness was diagnosed? If yes, what is the name of the child, the type of behavior change, when it occurred, and how long it lasted?

- Do you remember any behavior changes with the siblings after the illness was diagnosed? If yes, what is the name of the child, the type of behavior change, when it occurred, and how long it lasted?

APPENDIX E
SIBLING INTERVIEW GUIDE

Time of Diagnosis

How were you told about _____ illness? Can you remember how you felt?

What was it like for you when _____ was diagnosed with leukemia?

What was the hardest part for you around the time of the diagnosis?

What could have been done to make it better?

Family Life/Home Environment

What things have changed in your family since _____ became ill?

What was it like for you when _____ had to go to the hospital? Clinic?

Do you ever help with _____'s care at home or in the hospital?

Have you ever gone to the clinic with _____?

Can your family talk openly about your brother's/sister's illness or does everyone seem to keep their thoughts to themselves?

If you were trying to help another brother or sister of a child who was just diagnosed with leukemia, what kind of things would you tell them to expect to happen in their family?

Relationships

Are things different between you and your mother since _____ became ill? In what ways?

Are things different between you and your father since _____ became ill? In what ways?

Are things different between you and _____ since he/she became ill? In what ways?

No matter how much people love one another there are times when they get angry with one another. Tell me what makes you get angry or upset with your parents? brother/sister?

Who can you talk to when you get angry or upset?

Do your parents tell you what is going on with _____ illness and his/her treatment?

Personal

Tell me what it is like to be a brother/sister of a person with leukemia?

If you had to pick one thing which has been the worst part of having a brother/sister with leukemia, what would that be?

Have any good things happened to you or your family because of _____ illness?

Have you learned anything important from the experiences of having a brother/sister with leukemia?

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