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**NEW APPROACHES TO THE SUPPORTIVE TREATMENT OF SIBLINGS OF
PEDIATRIC CANCER PATIENTS**

City University of New York

D.S.W. 1986

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NEW APPROACHES TO THE SUPPORTIVE TREATMENT OF
SIBLINGS OF PEDIATRIC CANCER
PATIENTS

by
SUSAN JULIA BENDOR

A disseration submitted to the Graduate Faculty in
Social Work in partial fulfillment of the
requirements for the degree of Doctor of Social
Welfare, The City University of New York.

1986

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This manuscript has been read and accepted for the Graduate Faculty in Social Work in satisfaction of the dissertation requirement for the degree of Doctor of Social Welfare.

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DEDICATION

This work is dedicated to my brother, Frank Blum, who was the fundamental inspiration for this project. As my rival and protector, playmate and confidant, he taught me to appreciate the unique power and complexity of sibling relationships.

ACKNOWLEDGEMENTS

I want to thank the members of my project committee for their consistent interest, support and guidance.

Dr. Irwin Epstein, as my chairperson, helped with the initial formulation of the project and continued to offer invaluable advice and editorial judgment until its completion.

Dr. Kurzman and Dr. Mailick laid the ground work for my relationship with the Medical Center in which the project was conducted. Dr. Kurzman gave his time and insights generously and encouraged me to complete the work against great personal odds. Dr. Malick was creative, knowledgeable, consultant whose ideas have enriched the study and have made it more relevant to the field of social work.

To the professional and clerical staff at Hampton Medical Center, I offer my grateful appreciation for their flexibility, openness and willingness to do extra work.

My warmest thanks are reserved for my husband, Edgar, and daughters, Jane and Cathy, who tolerated a lot of tension and disorder for several years without losing faith, patience or pride in my work.

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CHAPTER I

PROBLEM FORMATION AND REVIEW OF THE LITERATURE

INTRODUCTION

REVIEW OF LITERATURE

- I. SIBLINGS OF PEDIATRIC CANCER PATIENTS
- II. SIBLINGS OF CHRONICALLY ILL CHILDREN
- III. SIBLINGS OF RETARDED CHILDREN
- IV. SOCIOLOGICAL AND PSYCHOLOGICAL STUDIES OF SIBLINGS
- V. IMPLICATIONS OF THE LITERATURE REVIEW

CHAPTER I

PROBLEM FORMULATION AND REVIEW OF THE LITERATURE

INTRODUCTION

Despite enormous advances in diagnosis and treatment, pediatric cancer has been cited by the American Cancer Society as the disease causing the greatest number of deaths among children between the ages of 3 and 14 in the U.S. in 1983, 84 and 85. Six thousand new cases were diagnosed in each of those years and the same number of new cases are anticipated for 1986.¹

It is well known that for all these thousands of patients and families "the rigors of medical treatment, the pattern of hospitalizations, remissions and relapses and the ever present fear of death require enormous psychological adjustment".² Offering effective psychosocial services to these families presents a major challenge to health care professionals.

New medical treatments which have become available in the past 3 decades have dramatically improved the life expectancy of child cancer victims but have also brought with them a new set of concerns and traumas. The need for frequent blood transfusions, costly and risky radiation treatments, the distressing side effects of chemotherapy such as hair loss, nausea and infection proneness of the treated child, have significant implications for the patient and his family members. These changes in medical

treatment methods call for concomitant changes in the psychosocial treatment of patients and families.

When cancers such as leukemia and solid tumors were inevitably fatal diseases with death occurring rapidly after onset of the disease, the psychosocial help offered was geared to helping patients and parents cope with death. The changes in medical treatment that enable children afflicted with cancer to survive for months or years albeit with frequent pain, sacrifice and uncertainty call for a psychosocial approach geared to helping patients and their whole families live with all that pain, sacrifice and uncertainty.

Reaching and helping the well siblings of the sick child represents the most difficult aspect of this challenge since so little is known about what siblings need and how they cope. The investigator's personal experience in the fields of health, mental health and child welfare suggested that the well siblings of pediatric cancer patients are at high risk for emotional impairment, yet receive almost no professional service or attention until they become symptomatic themselves, i.e. until they develop the social, emotional or physical difficulties which bring them to the attention of health or mental health professionals. This observation was confirmed by an exhaustive search of the literature and consultation with experts in the field of pediatric cancer.³

The recognition that siblings are excluded from the

medical and psychosocial support offered to patients and parents in the health care facilities that serve cancer patients is all the more startling when one considers the clinical evidence available in those facilities. Clinical observations indicate that:

"For the well sibling the illness of cancer means a loss of customary parental attention now focused on the leukemic child. During hospitalizations it means the parents' actual physical absence, role realignments within the family and changes in valued family activities and routines.

"The children must deal with a confusing array of feelings resulting from these and other consequences of the illness: anger toward the parents, increased rivalry and hostility towards the ill child- especially when he is in remission and supposedly well - followed by fear and often intense guilt when the leukemic child is again hospitalized."⁴

Two recent studies have shown that siblings suffer at least as much or probably more than patients in unattended emotional responses to the disease and disease process.⁵ Although the vulnerability of well siblings is attracting increased research interest, no systematic study to date has explored what the well siblings need and how their needs can be met so that their emotional impairment could be prevented.

As Lavigne and Ryan recommend: "Information is needed on changes occurring within the family, between family members and with peers that affects the siblings. Answers to such questions are essential to the development

of informed approaches to helping families cope with illnesses and handicaps."⁶

Bank and Kahn cited two major reasons why siblings have rarely been studied systematically by health care researchers. They claimed that in this culture dominant value is placed on the romantic relationship between parents rather than on fraternal ties between children. Secondly they noted that family size has diminished and the health care system is structured such that siblings are considerably less visible than they were a few decades ago.⁷ Sourkes offers another explanation for the neglect suffered by siblings. She suggests that the absence of a systems view of the family both in clinical practice and literature in part explains why "brothers and sisters stand outside the spotlight although they live through the illness with the same intensity as the patient and parents".⁸

Sourkes as well as several other researchers and practitioners have called for more focused attention on siblings and for the development of intervention strategies that will facilitate the healthy adaptation of siblings.⁹

Cain, Fast and Ericson conclude their study of sibling's disturbed reactions to the death of a sibling with the following statement: "A full preventive therapeutic approach to the dead child's siblings, integrated with assistance to the grieving parents remains to be carefully spelled out. But recognition of the need

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for such efforts represents a major step toward preventing what we elsewhere called the senseless arithmetic of adding newly warped lives to the one already tragically ended."¹⁰

Objectives of the Study

This study seeks to identify and explore the psychosocial needs of the well siblings of pediatric cancer patients and to develop a set of approaches for meeting some of these. The ultimate goal of the project is to prevent the emotional and physical impairment of well siblings and to improve the psychosocial adaptation of the pediatric cancer patient's entire family.

It is anticipated that the findings of this exploratory study will yield valuable information which can be used for designing services and programs that can achieve the goal of prevention on a large scale.

REVIEW OF LITERATURE

Review of the literature focused on clinical, research and theoretical material relevant to the study's purpose and primary objectives.

The literature reviewed encompassed published work in four major areas:

- I. Siblings of Pediatric Cancer Patients.
- II. Siblings of Chronically Ill Children.

III. Siblings of Retarded Children.

IV. Sociological and Psychological Studies and theories which were expected to shed light on general aspects of the sibling phenomenon and contribute to a better understanding of what one researcher aptly called "The Sibling Relationship: A Forgotten Dimension".¹¹

I. Clinical Literature On Siblings Of Pediatric Cancer Patients

In 1980, Sourkes noted in her seminal chapter on the Siblings of Pediatric Cancer Patients that clinical literature in this area may be classified into three categories:

"One set of articles presents observations on families with a section devoted to sibling behavior patterns and symptoms. Retrospective studies on sibling problems based upon parental reports, psychiatric records and sibling interviews comprise the second category. The third group of articles comprises accounts of individual psychotherapy with a sibling of a patient."¹²

The comprehensive literature review undertaken for this study confirmed the presence of the categories recorded by Sourkes but also revealed two further categories which represent important additions to

this neglected area of research and practice.

A fourth category consists of prospective research studies which focus on the siblings directly rather than tangentially, and use psychometric tests of the siblings in order to measure their adaptation to the afflicted sibling's illness rather than rely on parental reports or psychiatric records.

The fifth category consists of a small but encouraging number of articles which document efforts designed to provide services to the siblings of pediatric cancer patients.

Thus far, articles in the latter category stem primarily from the field of nursing.

The literature reviewed in the areas cited above will be summarized here with emphasis on the way the literature influenced the nature, design and content of the investigator's study. The research conducted to date on siblings of pediatric cancer patients will be discussed in greatest detail.

I. SIBLINGS OF PEDIATRIC CANCER PATIENTS

Observations of the Siblings Within the Family

The focus of these articles is on the effects of the illness-induced parental stress on the siblings and on the reactions and symptoms manifested by siblings, with some recommendations for management.

These articles examine the impact of the illness on the siblings from a variety of perspectives.

Cairns et al. in an ongoing program of research concerning the psychological ramifications of childhood cancer investigated the stress the illness imposes on various family members. They found that the financial burden of the illness has emerged as a major source of distress second only to the disease itself.¹³ To understand this phenomenon better, they conducted a pilot study in which six families of children in treatment for cancer reported their non-medical expenses and loss of pay for four consecutive weeks. Non-medical costs were selected for investigation since most families have at least some third party payment for medical expenses not covered. In contrast, non-medical expenses must be paid as they are incurred and are rarely if ever reimbursed. Cairns et al. found that for half of the families in their study the total financial impact of the illness tied up 35.6% or more of monthly family income. They concluded that due to the financial stress of having a child with cancer, parents and siblings may be deprived of the fulfillment of basic needs as well as the luxuries of life.¹⁴

Bozeman et al. conducted a study of the mothers of 20 children ranging from 1 1/2 to 6 1/2 who were hospitalized at Memorial Center for Cancer with a definitive diagnosis of acute leukemia. Initial interviews

were conducted with mothers of children who had been under treatment for as little as five days and as long as nineteen months. Later interviews occurred during hospitalization. The stage of treatment at the last interview varied from initial medication to the use of previously untried drugs due to failure to respond to all other forms of treatment. None of the mothers in the investigation was interviewed or observed during all phases of treatment but most were observed in more than one phase. The researchers vividly describe the enormous parental anxiety and stress which prohibited them from implementing a more rigorous research design that called for more frequent interviews and psychometric testing. With respect to siblings, Bozeman et al. found that the traumatic impact of a fatal childhood disease upon mother had very significant repercussions on siblings. The heightened nervousness reported by the mothers, which prevented them from concentrating on previously enjoyed activities, and routine household chores, was accompanied by an inability to control feelings of irritability toward the healthy children.

During periods of remission at home, mothers were faced with the problem of whether they should favor the ill child in matters of care and discipline. Five mothers attempted to maintain previous familial relationships and standards of conduct unchanged. Disciplinary measures, the usual balance of attention between children and bases of

special privileges were continued insofar as possible unchanged. Ten mothers altered their relationships with the sick child to provide the attention that was medically necessary, dispensed with discipline or provided special entertainment or presents. Two had no other children. Three mothers required special consideration for the ill child from the other children. In contrast, five mothers with other children expressed feelings about the unfairness of the situation to the well siblings and made some efforts to compensate them for the special privileges afforded the ill child.¹⁵

Bozeman's study alerts the reader to the differences in the way the sick child and his normal siblings are treated by their mothers after one child is diagnosed to have cancer. The study also highlights the risk that the healthy siblings become the targets of displaced maternal anxiety and irritability caused by the stress of the illness. This risk is also noted by Poznanski in a different study.¹⁶

Share, in a comprehensive review and analysis of the literature prior to 1972, examines the relationship between styles of family communication and the stresses and anxieties experienced by the sick child and his family. She discusses the two opposing modes of communication which have been advocated, the protective approach in which the ill child (and his siblings) are shielded from knowledge of the disease, diagnosis and prognosis - and the open

approach which encourages provision of an environment in which the child feels free to express concerns and ask questions about his condition but are not included in the family problem.¹⁷

She concludes her analysis with a strong indictment of the protective approach, citing various studies of the effects of both approaches. She quotes several authors regarding the protective approach.

"The end result then is that the child feels lonely and abandoned at the very time when he is most in need of meaningful communication with a trustworthy adult (Vernick & Karon 1965; Binger et al. 1969). Thus he derives his own distorted conclusions about the cause of his physical condition, begins to distrust the thought that others are genuinely concerned with his welfare, and feels increasingly threatened by his seeming inability to make sense out of the many conflicting messages given to him by his environment."

"Similar consequences are noted for the well siblings who observe the lack of "normal" family life but are not included in the family problem. Thus they often perceive the attention given to the leukemic child as indicating the parents' rejection of themselves and are left alone to deal with the thought that they too will become seriously ill or die (Binger et al. 1969). (McCollum & Schwartz 1972) Coping with these byproducts of the protective approach argues the open view is the ill child's and siblings' most difficult psychological task."¹⁸

A chapter devoted to siblings of the dying child by Lindsay and MacCarthy presents sibling issues within a developmental framework. The authors synthesized their understanding of developmental theories and knowledge

derived from research on childhood illness to conceptualize the impact of a child's dying on siblings at different stages of psychosexual development. They state that the sibling who is an infant at the time another child is ill is at the highest risk. At a critically formative time, the mother because of her preoccupation with patient may be unable to adapt to and be aware of the infant's cues. The toddler, too young for a comprehensive verbal explanation, may experience the parental preoccupation as rejection. The child then may feel badly about himself and regress in development. The child who is older and verbal may feel a complex of resentment, anger and guilt in addition to the rejection and must learn to cope with the elevated level of anxiety in the family. This child may act out as a defense against depression or withdraw into daydreams and anxious thoughts. In turn, school performance can be adversely affected. Psychosomatic symptoms often set in; the child sees the illness as a means of getting attention yet is simultaneously afraid of being ill like the patient. The sibling may show a preferred stress reaction such as an exaggeration of asthma. Feelings of preoccupation and low self worth may lead to increased accident proneness. School phobia, the endpoint of a continuum of disturbance represents the child's cumulative anxiety about separation from mother, about illness and the fear of the power of the unacceptable anger toward the patient and the parent. The older child may take over care of the patient in the form

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of identification with parents. Lindsay and McCarthy point out that this care giving may be a reaction formation, a costly defense against acknowledging intense resentment.¹⁹

If the sibling is older than the patient, then rivalries from the time of the sick child's birth may be reactivated or intensified. Similarly, Weiner (1970) contends that competition and rivalry are developmental aspects of the relationship between a school aged child and a younger child and may be exacerbated by the stress of the illness. If the sibling is younger than the patient, increased envy may arise around the patient's privileges and accomplishments.²⁰

Lindsay and McCarthy emphasize the ebb and flow of the parents' preoccupation with the sick child. Its intensity is highest at the time of diagnosis and during exacerbation or relapse of the illness. They point out that the parents' loss of confidence in parenting skills once they have a sick child may generalize to a feeling of inadequacy with the siblings as well.²¹

In a later paper, Kagen-Goodheart describes the role of the mental health professional in helping the sick child, his parents and siblings manage lengthy and difficult outpatient medical care, which is the hallmark of contemporary cancer treatment. The author sensitively describes the conflicts faced by all family members when the patient leaves "the secure limits of the hospital"

after the diagnosis of cancer is confirmed.

The siblings, especially if they are young, confront an extremely difficult transition. They expect that all will go on as before, but that is only an illusion. The parents may still treat the patient in a very special way and familial routines and expectations change in response to the medical needs and realities. To prevent family conflicts and emotional problems in siblings, Kagen-Goodheart suggests that the siblings can be reassured that they too would get the same attention if they were sick, and that their cooperation is appreciated. She also urges that parents provide siblings with the opportunity to express feelings of resentment and jealousy in private, and that they reiterate to siblings that bad behavior did not and cannot cause illness.²²

Spinnetta, Kung and Schwartz in their handbook for parents of leukemic children echo Kagen-Goodheart's plea that siblings should be reassured that the disease was not their doing, and that it is not contagious.²³

Kagen-Goodheart also makes a significant point not mentioned in most articles. The jealousy, resentment and anger is not unique to healthy siblings. It's often two-directional. The patient may express anger toward the sibling for being well. This possibility implies that siblings must not only cope with their own feelings of anger and guilt, but must also learn to deal with potential overt hostility from their sick sibling who finds life

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dramatically altered after learning that he has a serious illness which may curtail his activities, expose him to painful treatments, frightening changes in his body, and the possibility of a shortened future.

Although there are differences in the purpose and perspectives of the large volume of articles which describe familial attempts to cope with pediatric cancer, there is general agreement about the severity of the stress and challenge which all family members face. Futterman and Hoffman best summarize this agreement.

"Coping with the fatal illness of a child has been considered one of the most poignant and stressful events encountered by families in our society. The crisis precipitated by such a harsh and unexpected threat profoundly affects the immediate and long range adaptation of family members. Family equilibrium is endangered. Coping strategies and adaptive mechanisms which were useful in dealing with previous developmental and adaptive tasks are challenged and resources are tapped that may not have been formerly apparent."²⁴

Retrospective Studies

Binger et al. conducted the first retrospective study which examined the impact of a child's death from cancer upon his siblings. The investigators contacted 23 families whose child died from leukemia between January 1964 and December 1966. Twenty families agreed to

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participate in parent interviews. In approximately half of the families studied, one or more previously well adjusted siblings showed significant behavioral disorders which indicated difficulty in coping. The problems included, enuresis, depression, severe headaches, school problems, separation anxiety, somatic preoccupations and intense feelings of fear and guilt. These symptoms increased in severity after the child's death.²⁵

In a report which followed the initial publication of their findings, Binger offered further analysis and interpretation of their data. He indicated that the siblings' reactions to the illness and death were multidetermined. Stage of development, family response of adaptation or conflict around the illness and the natural history of the illness were all important factors. After the patient died the siblings' concern centered on their responsibility for the death, fear of being next to die and resentment toward the parents for their preoccupation and inability to protect the child.

Binger provides several case vignettes which describe the siblings' varied manifest reactions to the patients' death. Certain children who appeared unconcerned at the time of the death overreacted to subsequent loss. Binger concludes that the reactions included "immediate physical and psychological symptoms associated with grief, which in a number of children continued toward enduring symptoms with distortions in character structure. He

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poignantly notes "Death is the end of life but not the end of relationships especially ambivalent ones, and mourning may be postponed for several developmental epochs and sometimes for eons. Such children may become vulnerable adults with a disposition to depression".²⁶

Cain, Fast and Ericson studied children's disturbed reactions to the death of a sibling. They analyzed the inpatient and outpatient psychiatric records of 58 children ages 2 1/2 to 14 who experienced the death of a sibling due to a variety of causes (acute and chronic illness, accident, etc.). The sources of their data included intensive outpatient psychotherapy records, referral materials, developmental histories, psychological tests, interviews, and in 11 cases full materials from prolonged inpatient treatment.

The authors carefully specify that in the cases they reviewed there was evidence that some though by no means all the major symptoms and character distortions of the patients were substantially related to the death of the sibling.²⁷ The reactions to the death covered the whole range of areas. Cognition, belief systems, superego functioning and object relationships were variedly involved. Problems were on intrapsychic, family, peer neighborhood, school and community levels. Guilt laden reactions were pervasive.

At least half of the children expressed much guilt even 5 years after the sibling's death. Several children

openly verbalized that they felt responsible for the death and should have died also, or instead of the sibling. Their deteriorating school performance was viewed as further proof of their worthlessness. Others manifested guilt through withdrawal, suicidal ideation, accident proneness or acting out. Distorted concepts of illness and death were common. Those children who had been treated to conventional saws about people not dying until they are very old were clearly struggling with the contradiction their sibling's death represented, and its corresponding undermining of their confidence in adult pronouncements. A few siblings solved their agony temporarily by saying, "You can't die until you are at least 9, the dead sibling's age".²⁸ Death phobias were evident in the responses of virtually all the children.

Disturbed attitudes towards doctors, hospitals and religion were also widespread. Cain et al. describe this vividly.

"In the majority of cases the surviving children's fear of doctors was greatly heightened. Hospitals were even more terrifying and going to a hospital was equated with death. This reaction was not an isolated one. Often the parents distrusted and blamed the doctors and hospitals and later some remained reluctant to let their other children be hospitalized for necessary medical procedures."²⁹

The researchers cite the following factors as key

determinants of children's responses to the death of a sibling. The nature of the death, age, sex and characteristics of the child who died; the sibling's actual involvement in his sibling's death, the child's pre-existing relationship to the dead sibling, the immediate impact of the death upon the parents; the community's reactions; the impact of the death upon family structure; the availability of various substitutes to both child and parents; parents' enduring reactions to the child's death; major concurrent stress upon the child and family. The developmental level of the surviving child, particularly his cognitive capacity to understand death was also viewed as a crucial determinant.³⁰

This sobering study was concluded with a call for related investigations into the factors differentiating relatively successful adaptations to sibling loss, versus the pathological reactions manifested in the Cain study as well as others.³¹

Cain and his colleagues regard such clinical investigations as having potential preventive value.

Their logic is unassailable. Even without further research, their findings demonstrate that the alleviation of guilt and prevention of distortions about illness, doctors, hospitals and death must begin long before the sibling's death, preferably through honest and supportive interactions between siblings, parents and health care professionals while the sick child is still alive,

reinforced through post death follow up contacts as recommended by Adams and Kaplan.³²

Two other retrospective studies focused on a different sibling population. They sought to assess the impact of childhood cancer on siblings whose sick sibling did not die.

Gogan, Koocher et al. conducted one session interviews with 13 siblings between the ages of 8 and 28 with a median age of 17. All were born prior to the patients' diagnosis which had to occur at least 5 years previously. The median age of the siblings at the times of diagnosis was 4. The average number of years intervening between initial diagnosis and time of interview was 13.5 years. It is crucial to note that all the patients were alive and were part of a long term survivor group followed at the Sidney Farber Institute in Boston, Mass.³³

The investigators found that the siblings' understanding of the patients' potential fatality increased as a function of their present age and age at diagnosis.

Most of the siblings minimized the impact of the illness at the time it occurred. Some rivalry was described, but few feelings of guilt were expressed, with the exception of one girl in the sample who harbored feelings of responsibility for her brother's illness for several years. No one claimed to remember feeling abandoned. Interestingly, some of the direct quotes from siblings imply the presence of more stress than was

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acknowledged. "Seven year olds, and young kids don't have feelings about such things" was a common refrain."

One brother, when asked if the patient received special privileges during or after his illness replied that no one in the family got special privileges as all were taught to be self reliant. To illustrate, he told the interviewer that, "Despite his own stuttering problem he refused to go to a specialist because his father taught him to be self reliant".³⁴

Gogan et al. in evaluating their own study pointed out that apart from the limitations of small sample size, the combined effects of the many intervening years since diagnosis and the young age of the siblings at the time of diagnosis undoubtedly contributed to significant distortion.³⁵ They also recognized that retrospection minimizes the stress accompanying the actual experience and called for more large scale retrospective and prospective research which can be used to design effective interventions for helping family members through the cancer experience.

Koocher and associates headed one of their own recommendations and followed their initial study with a much larger project designed to study the psychological, and social consequences of childhood cancer.

The new sample included 117 childhood cancer survivors whose diagnosis and treatment had begun at least 60 months earlier.

Among other objectives, the study sought to formulate recommendations for the care of future childhood cancer patients with the goal of reducing long term psychological problems.³⁶

The researchers interviewed 101 siblings (ages 7 - 34) at time of interview, using a semi structured format including forced choice and open ended questions.

Siblings were asked to describe their current and past experiences and feelings about the patient and the illness.³⁷

Approximately 1/3 of the siblings stated that they had worried about getting cancer themselves during the patient's treatment. Almost 1/4 said they had felt jealous of the patient during the time of active treatment. 19% admitted some residual feelings of jealousy.³⁸

Some siblings reported positive aspects of the cancer experience, such as enhancement of their own personal growth and development of coping skills.

Koocher's summary of the sibling interviews contains two specific items which are relevant for the targeting of this study's interventions. "It may be that siblings aged 6 - 10 at the time of cancer treatment are particularly vulnerable to feelings of rivalry and attendant difficulties. Many of the siblings' problems could apparently have been prevented or ameliorated by providing factual information at the time of diagnosis and treatment."³⁹

Prospective Studies

Kaplan et al. conducted the first prospective survey designed to describe the impact of a serious illness, childhood leukemia on the health and functioning of family members, including healthy siblings.⁴⁰ Forty families whose child received medical treatment for leukemia at the Department of Pediatrics, Stanford University Medical Center were followed regularly from the time diagnosis was confirmed until three months after the leukemic child died.⁴¹

They found that only 12% of the families surveyed managed to emerge from the illness experience without serious damage to effective family functioning or without multiple problems among the survivors, problems precipitated or aggravated by the illness. Marital problems, health problems and functional problems were present in most families.⁴²

Among the 97 surviving siblings, 43 were reported by parents to have one or more adjustment problems. Serious parent child conflicts, school problems and morbid grief reactions ranked highest on the problem list.

Kaplan et al. also found that family coping responses that manifested themselves immediately after the diagnosis were useful in predicting stress outcome. They, therefore, conclude that "optimal period for intervention is during the early acute stage of the crisis, immediately

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following confirmation of the diagnosis, when the family is making those decisions associated with maldaptive coping and stress outcome".⁴³

Two later prospective studies used more rigorous research designs to measure sibling adaptation. Cairns et al. administered a variety of objective and projective psychological tests to school aged cancer patients and their siblings from 71 families, whose child was receiving cancer treatment at Kansas Medical Center. The patients were studied to provide a reference point from which to evaluate their healthy siblings.

The results indicated that:

"siblings showed even more distress than the patients in the areas of perceived social isolation, perception of their parents as overindulgent and overprotective of the sick child, fear of confronting family members with negative feelings and concern with failure (older siblings). In other areas such as anxiety and vulnerability to illness and injury the patients and siblings' experience appeared very similar."⁴⁴

In a multifaceted 3 year study of cancer patients and their families at Children's Hospital in Los Angeles, Spinnetta et al. reported similar findings.

The authors who pioneered rigorous comprehensive psychosocial research in childhood cancer administered a longitudinal series of tests to each sibling and patient in a variety of settings and disease related circumstances.⁴⁵ The health care teams were also asked

to evaluate each family's adaptation.

Spinnetta found that not only did the siblings score at significantly lower levels of adaptation on the criterion measures of communication, emotional tone and self image, they also scored at lower levels of adaptation in specific tasks and in response to individual tests. Findings include the following age-related differences between siblings and patients:

Ages 4 - 6

The sibling's level of self-concept was significantly lower than that of the patients. They also viewed their parents as more distant psychologically than the patients.

Ages 6 - 12

Siblings scored at more maladaptive levels in items relating to anxiety and depression than the patients. They too viewed their parents as more distant psychologically than did the patients. Overall the school age siblings' adaptation to the cancer experience was significantly below the patients'.

Young Adults Aged 13 - 18

Siblings perceived their family as significantly greater in conflict and lower in cohesion than did the patients.⁴⁶

Spinnetta is cautious but eloquent in interpreting his findings. "Although the siblings did not fare worse

than the patients on many of the items, they did so on items of central concern. When siblings score at significantly less adaptive levels than patients, concern is raised regarding the fact that their needs are being met adequately."⁴⁷ Citing other measures which indicated that the siblings lose out both when the patient is in crisis and when he is doing relatively well, Spinnetta suggests ways in which the extended hospital based health care team might focus on sibling needs, either through direct service (play groups, rap sessions, etc.) or by calling the siblings' needs to the parents' attention.

His call for professional intervention is powerful and unequivocal:

"All family members suffer when a child is diagnosed with cancer. In its attempts to keep marital relationships alive and vital and to help the children with cancer cope with and master the illness, the medical team should not ignore the needs and concerns of those persons who will in most cases live longest with the memories and concerns relative to the cancer, the siblings of children with cancer."⁴⁸

RECOMMENDATIONS FOR INTERVENTION

Several authors whose work was reviewed made specific recommendations for addressing the needs of siblings. Lindsay and McCarthy stress that siblings should get information directly from the doctors or their parents in order to minimize their misconceptions about the illness. Their visits to the hospital should be encouraged

and they should be included in certain ward activities. The authors also suggest that parents need help in clarifying priorities in the needs of the patient and the siblings.⁴⁹

Weiner makes similar recommendations. After pointing out that guilt in siblings will lead to aggressive symptoms, nightmares and active aggression, he suggests that by staff's expressed interest in siblings, parents will be encouraged to focus on the needs of siblings. He also points out that the siblings' attendance at the funeral provides an important concrete experience to counterbalance their fantasies about death.⁵⁰

Kagen-Goodheart, Spinnetta, Kung and Schwartz emphasize the importance of reassuring siblings that they are not responsible for the disease and that the disease is not contagious. They also recommend that parents and professionals find ways to provide siblings with the opportunity to express their feelings and fears.⁵¹

A very recent prospective study of siblings' emotional responses to the cancer experience contains several recommendations for social work intervention with siblings.

Koch-Hattem interviewed 33 siblings of 60 randomly selected cancer patients who had been diagnosed between six and thirty six months prior to the study and remained in treatment at a major urban facility. The patients had to be in remission in order to be included in the study. The

siblings had to be seven years or older in order to be included. The mean age of the patients was 8.3 years where as the mean age of the siblings was 12.1 years. 27 of the siblings were girls, 13 were boys. 27 of the 33 siblings were older than their brother or sister who was the patient.

The siblings were interviewed in their homes. The interview schedule contained 30 forced choice questions concerning changes experienced by siblings after the diagnosis of cancer. The questions fell into five categories: affect, behavioral symptoms of depression, responsibilities and restrictions on activities, and conflict within and outside the home. The siblings were also asked open-ended questions about how they coped with the changes they experienced. Koch-Hattem found that her findings supported those of previous studies. Affect dominated the siblings' descriptions of the changes that had followed the diagnosis of pediatric cancer and the ways in which they coped with these changes. She found that: Although the emotions that siblings reported as increased may be considered negative (e.g. fear and sadness), these children also appeared to be able to use emotional expression to cope with their negative feelings. The majority of siblings in the study who acknowledged feeling bothered, sad or angry, indicated that they coped with these feelings by emoting, or giving vent to them. For example, seven of the 29 siblings who responded to the

question about coping with sad feelings said that they emoted. "Sometimes when I feel sad, I storm out of my room or sometimes I just scream or yell or kick the door."

The siblings were divided in their responses on how they coped with feeling angry. 13 out of 27 said they emoted, another 13 siblings avoided expressing their anger. I try not to be angry, was a typical comment.

Koch concluded her study with the recommendation that social workers, who are often the only psychosocial professionals in the hospital with access to the patient's family should use this access for facilitating the emotional adaptation of siblings. Her suggestions for social work intervention include:

1. providing educational experiences for parents with the goal of enhancing their ability to foster the healthy child's adaptation.
2. arranging question and answer sessions for siblings with physicians to learn more about cancer and its treatment.
3. linking healthy children in different families to one another.

Koch-Hattem recognizes that direct intervention such as establishing sibling support groups should also be considered. She challenges social workers to be creative in developing services for the sibling population.⁵²

Programs of Intervention Offered to Siblings

Reports of sporadic attempts to meet the needs of siblings began to appear in the literature in 1981. Two sibling group programs have been described thus far.

Kramer and Moore offered a one-time summer program in California. They mailed letters to the brothers and sisters of pediatric oncology patients diagnosed within the past 3 years, inviting them to a special summer sibling program. A total of 50 siblings of various ages participated in the program which was primarily educational although it also sought to provide siblings with an opportunity to discuss their feelings and concerns in a therapeutic, supportive environment.

The program content and goals are fully described, in their article but the frequency and length of meetings are not reported. Separate sessions were planned for younger and older siblings but due to geographic limitations, the majority of siblings attended the program on the day the family's child with cancer had a scheduled appointment. This resulted in a fairly diverse group on several occasions.

The program was evaluated very favorably both by participants and their parents. Discussion on the psychosocial aspects of the program was especially well received by children ages 9 and older who stated that they gained reassurance and support by sharing feelings and gaining information.

The majority of parents noted that discussion about the cancer illness increased following the program.

There was also more sibling involvement in the sick child's care, a development parents welcomed.⁵³

A different sibling group program was offered at Case Western University School of Medicine, Department of Pediatrics and Social Service.

Siblings of pediatric oncology patients in active therapy met as a group for 1 1/2 hours after school for five consecutive weeks, with the oncology social worker and nurse oncologist. Simultaneously two other nurses met with the parents. Ten siblings between the ages of 9 and 12 participated.

The program began after the pediatric oncology staff identified several siblings who exhibited problems such as regressive or angry interpersonal behavior at home or at school. Eight of the twelve families approached by mail agreed to their healthy children's participation.

The parents who responded positively to the group program indicated that the siblings exhibited a variety of problems, including attention-seeking behavior, withdrawal, sibling refusal to discuss the patient's illness and difficulty in dealing with peers. The authors note that the consenting parents were aware of the problems but were unable to formulate solutions.

The group program sought to provide a support group for siblings and to provide information regarding various treatment regimens. Time was structured into a discussion period and tour of the hospital area related to the

patient's physical care.

At the end of the program participants were asked to evaluate the experience. Both groups found it beneficial. Parents felt the sibling group gave them an opportunity to do something for their healthy children. All the siblings except one asked for more meetings. Their responses stressed the value of "belonging here" and finding other kids in the same situation.

Interviews conducted one year later confirmed the positive effects of the group. Attention-seeking behaviors were found to be essentially nonexistent either at home or at school and siblings continued to be able to verbalize their attitudes about the illness and hospital related matters. The group seemed to have been especially helpful to siblings whose brother or sister died in the interim.⁵⁴

Cunningham et al., conclude that although their group size was small, the program's value was considerable. They feel that sibling group intervention can help minimize guilt and resentment, relieve anxiety and route emotional concerns into more constructive channels. They recommend the incorporation of sibling groups into a comprehensive approach to pediatric oncology patients.⁵⁵

Cimini's unpublished doctoral research represents the most recent known effort to provide services to siblings of cancer patients. Cimini offered a group program to siblings and evaluated its effectiveness.

The subjects in Cimini's study consisted of thirty siblings of pediatric cancer patients who were receiving treatment at the Albany Medical Center. The sample was equally divided between boys and girls who ranged in age from seven to fourteen. The mean ages of the siblings was 9.3, the median age, 9.5. Fifteen siblings were randomly assigned to a comparison condition. The fifteen siblings in the experimental condition were asked to listen to a series of presentations, one describing the workings of a hospital, a second describing childhood cancer and a third addressing how they might most effectively cope with cancer in a brother or sister. A measure of coping as well as self report measures of anxiety depression and fear were administered to all subjects both before and after the intervention package. In addition, a more detailed picture of the siblings' areas of concern was obtained through a semi-structured interview developed by the investigator. Parent ratings of the subjects were obtained through their completion of the Achenbach and Edelbrock Child Behavior Checklist.

Cimini's analysis of interview data across subjects indicated that the siblings in her sample experienced psychological and behavioral changes related to the diagnosis of cancer in the siblings.

These disturbances were found to occur in the areas of parent-child relationships, anxiety, depression and to a

lesser extent, through acting out behaviors. Repeated measures and analysis of variance revealed statistically significant differences in anxiety and depression scores between experimental and control subjects from pre to post intervention. An analysis of fear scores did not reveal differences between experimental and comparison groups in the predicted direction but an examination of items assessing medical fears showed a trend toward a decrease in medical fear scores from pre to post intervention in experimental subjects.

There were no statistically significant age or gender differences on any of the above measures.

Analysis of data from the coping Skills Questionnaire revealed a statistically significant difference between experimental and comparison groups from pre to post intervention suggesting that the subjects who participated in the information support intervention showed greater coping scores after the intervention, than did comparison subjects. Data obtained from both participants and parents indicated that "The most important factor which was attributed to the success of the intervention was the provision of the opportunity for children to interact with other children in similar situations."⁵⁶

Cimini found that the parents rated the program helpful. Thirteen of the fifteen parents who completed the Parent Feedback form indicated that they noticed behavioral changes in their healthy children as a result of the

intervention (e.g. decreased hostility and sadness and increased helpfulness at home.). Cimini concludes from her research that sibling information support groups which can be run by nurses, social workers, psychologists or doctors, represent a potentially valuable form of intervention for siblings of cancer patients. Her findings are consistent with those of Chinitz (1981), Azarnoff (1974), Huges (1982), and McKeever (1983). These authors in the field of chronic illness in children have suggested that providing support and information to the siblings of children with chronic illness may help to alleviate anxiety, depression and fear and might enhance adjustment.

A condensed report of Robin Kramer's master's thesis must be listed as part of the literature geared toward specific interventions for siblings.

Kramer's well conceptualized descriptive, exploratory study of siblings' perception of what it is like to have a brother or sister who has cancer contains a list of creative practical interventions which nurses can undertake to alleviate the stresses experienced by many healthy siblings.

Kramer's work, combined with that of other nurse researchers who studied siblings suggests that nurses and social workers may be natural allies in the development of a true family-centered approach to pediatric oncology patients.⁵⁷

The psychosocial knowledge emphasized in their

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training, coupled with the public health tradition of their respective professions may explain these two professions' sensitivity and commitment to serving all family members when one family member is ill.

II. SIBLINGS OF CHRONICALLY ILL CHILDREN

Systems theory, crisis theory and family theory all postulate that the concept of the family as a system implies that a change in one member of the family brings about a corresponding change in the rest of the system.

Over the past 20 years, these theories have gained considerable respect and interest in professional circles. This interest is reflected in a growing number of research studies which examine the impact of chronic illness on all members of the family, resulting in a shift from the narrow focus on the mother-child dyad which characterized research in earlier years. Unfortunately, the literature on siblings is still at a rudimentary level of conceptualization and methodology.

Many studies merely catalogue a list of problems encountered in healthy siblings and relatively few attempt to identify whether birth order, sex, nature and severity of the illness or other variables affect the prevalence and seriousness of the siblings' difficulties.

Methodological flaws such as small samples, absence of controls, non-randomized sampling techniques and reliance on parental and professional observations and

interpretations further limit these studies' scope of applications.

It was particularly distressing to note that every study which attempted to use an objective measure of sibling adjustment used a different instrument so that no valid comparisons are possible since the authors measured different aspects of behavior or adjustment.

Futhermore, no research has been replicated to date, so that the findings cannot be generalized with any certainty. Nevertheless, taken cumulatively, the existing research strongly suggests that siblings of chronically ill children are a population at risk, not inevitably for severe psychopathology, but almost certainly at risk for a great deal of anxiety, confusion and personal suffering.

Coddington, in a survey of life events as etiological factors in childhood disease found that serious sibling illness requiring hospitalization ranked among the most stressful of 42 life events in a survey sample of 3,620 children ranging in age from preschool to senior high school. The survey sample was selected to represent a valid cross section of the population in the state of Ohio.⁵⁸

In an early study of diabetic children and their normal siblings, Crain Sussman and Weil found that there were not statistically significant differences in the social-psychological functioning of diabetic children and non-diabetic siblings who were tested in a metropolitan

diabetes research clinic. The cross-sectional study sample consisted of 19 diabetic children and 16 non-ill siblings, aged 8 - 11.

The instruments used measured self-esteem, academic achievement, satisfaction with behavior, and level of aspiration as indicators of social-psychological function. The study also observed and rated maternal attitudes and practices towards diabetic, and healthy children to determine the relationship between mothers and children. It was in this area that differences were most striking. The mother-child relationship was found to be significantly different for the diabetic child as compared to the non-diabetic sibling. Mothers were found to have a much closer, intimate, expressive relationship with the diabetic children, than with the non-diabetic siblings.

Since maternal attitudes and practices were viewed as highly significant in the children's personality and social development, Crain et al. concluded that the illness of the child may have an ultimately more deleterious effect upon the non-ill child than upon the ill child. They, therefore, called for more research, and more critical attention focused upon the non-ill sibling in the families of chronically ill children.⁵⁹

In a different study of diabetic children Cadarang et al. examined the effects of a child's diabetes on the cognitive ability to the sick child's siblings. Their findings included the observation that such siblings

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conceptualized illness less accurately than do a group of peers with healthy siblings.

This finding was attributed to the decalage phenomenon described by Piaget in which stress acts as an intrusion factor to produce lower levels of general cognitive function. The finding suggests that the long term stress related to the effects of a sibling's diabetes may interfere with a child's cognitive ability and academic performance in an ongoing manner.⁶⁰ Academic problems among siblings of handicapped or chronically ill children have been reported in numerous studies, lending weight to Cadarang's findings.⁶¹

In one of the relatively few studies using control groups, Lavigne and Ryan used parental responses to the Louisville Behavior Checklist to compare the adjustment of 156 siblings (ages 3 - 13) of hematology, cardiology and plastic surgery patients followed at a large children's hospital with a control group of 46 siblings of healthy children.

On the basis of rigorous analysis of their data they concluded that there was not difference between the illness groups and the healthy controls on aggression, hyperactivity and learning disability scales. However, the siblings of all three groups of chronically ill children were significantly more withdrawn and irritable than were the siblings of healthy children.

Some of the specific illness related findings are

worth noting because of their implication for this project. The siblings of plastic surgery patients were most withdrawn and irritable and had the highest degree of emotional behavioral problems in the youngest age group (3 - 6).

In the 7 - 13 age group, the brothers of hematology patients showed significantly more behavioral problems than did the sisters, (the hematology patients all had leukemia or other forms of childhood cancer).

Lavigne and Ryan speculated that the elevated incidence of behavioral signs of psychopathology in the siblings of plastic surgery patients may in large part be due to the stigmatizing effect of a visible illness. Goldberg has already shown that patients with visible burns evidence more maladjustment than patients with "invisible" but more handicapping congenital heart defects. It is possible that the social discrimination which results from visible handicaps also affects the siblings.⁶¹ This assumption is consistent with Sourke's observations derived from her psychotherapeutic work with siblings of cancer patients. She found the "visibility of the illness" as a source of embarrassment and anxiety one of the major themes in siblings' preoccupations.⁶²

To explain the sex related differences among the siblings of hematology patients, Lavigne and Ryan speculate that certain personality traits common to boys (e.g. activity levels) may make them more vulnerable than girls

at times of family stress. As a corollary they suggest that girls may have certain personality traits which coupled with socialization into traditional sex roles may enhance their ability to cope and assume the increased responsibility demanded by a sibling's illness.⁶³

Breslau, Weitzman and Messenger question Lavigne and Ryan's findings and interpretations. Their study of 239 families of pediatric patients with cystic fibrosis, cerebral palsy, myelodysplasia and multiple handicaps receiving care in clinics of two Cleveland teaching hospitals included several items related to the psychological functioning of the patients' normal siblings. Psychiatric Screening Inventories completed on the patients' normal siblings (ages 6 - 18) was compared with data on 1,034 randomly selected children from a cross section of Manhattan households.

Breslau and her colleagues found that the proportion of siblings with serious psychological impairment was not significantly different from the Manhattan sample. The siblings of disabled children actually fared better than control subjects on isolation. On the other hand, the siblings of the disabled scored significantly higher than the comparison sample on the mentation problem, self-destructive tendency, fighting and delinquency subscales.

Since different instruments were used in these two studies, different aspects of sibling behavior were

measured so that the results cannot be properly compared.

Breslau's findings about the interaction effects of birth order and sex on sibling adjustment were in the opposite direction from those of Lavigne and Ryan. Breslau found that among siblings younger than patients, male siblings had greater psychological impairment, whereas the reverse was observed in females. This was in sharp contrast to Lavigne and Ryan's findings. Breslau et al. also question Lavigne and Ryan's interpretation of the importance of the visible manifestations of an illness. When the data was analyzed using sophisticated statistical techniques the physical stigmata of the patient population in Breslau's study had no significant impact on the siblings' psychologic functioning.

Breslau et al. also maintain that their research does not give consistent support to the widely held assumption that normal siblings tend to be neglected because of disproportionate parental attention and care given to the sick child.

They are concerned, however, about their finding that the siblings of disabled children scored significantly higher than controls on two measures of aggressive behavior, interpersonal aggression with peers and at school.

They urge that research on the effect of childhood disability on siblings should examine explanations other than parental inattention to account for this finding.

They immediately offer two alternative explanations worthy of serious pursuit; the first, that the mother's physical and mental health is adversely affected by the burden of the sick child's care, and that her impaired health rather than inattention then affects the siblings, the second that the disabled children affect their normal siblings directly in the realm of body language or learned behavior.⁶⁴

The Lavigne and Breslau studies exemplify some of the inconsistencies and contradictions which characterize much of the sibling literature. They also highlight the common use of parental reports of siblings' behavior as a measure of sibling adjustment.

Tew and Laurence were two of the few researchers who used instruments which were free from parental bias. Tew and Laurence studied the intelligence and adjustment of 59 children with spina bifida and their siblings, matched with 59 control children and their siblings. The assessment of sibling maladjustment was largely confined to school behavior through the use of the Bristol Social Adjustment Guide, which was completed by the teacher. The frequency of maladjustment in siblings of the children with spina bifida was almost four times higher than in the siblings of normal children. No differences were observed in the siblings scores whether the spina bifida child was at home or in a residential school.

The birth rank of the sick child was not found to

influence the siblings' adjustment.

Unexpectedly, Tew and Laurence found the children with very slight handicaps were likely to have the most disturbed siblings, followed by the severely handicapped group, far below the moderately handicapped group. They did not attempt to explain this phenomenon.⁶⁵

A different study of the families of handicapped children found that rank was a significant factor in sibling adjustment. Berggreen in her clinical study of 20 multi-handicapped children aged 3 1/2 to 15 receiving day care at Children's Hospital in Denmark found that of the 24 children younger than the patients, 35% of the siblings, male and female exhibited behavior problems which were related to the sick child's handicap. Her overall findings revealed that 29% of the children about the same age as the handicapped child had psychiatric problems which appeared to be directly or indirectly related to the presence of a handicapped child in the family.

Berggreen concluded that "the prospects for normal siblings seem to be the worst in families which there are only two siblings or when the normal siblings are much the same age as the handicapped child."

In her view, siblings in these families must compete for parental attention and affection with the handicapped child in a competition they cannot win. "If the handicapped child requires much care, then even parents with robust physical and mental health will have difficulty

in fulfilling their obligations to both children."⁶⁶ 46

Berggreen's study also revealed that a high percentage of siblings older than the handicapped child chose careers which involved the care of handicapped children. Similar results can be found in the literature of siblings of the retarded. This finding raises interesting questions about the possibility that normal siblings are programmed to be life long caretakers as a result of their own childhood experience with a handicapped sibling.

Prevalent Themes in the Literature

Since so much of the literature was contradictory, and did not contain findings which could be generalized, the articles on siblings of children with a chronic illness or handicap were re-examined to see whether they contained information which could explain the prevalence of sibling anxiety and isolation described in the pediatric cancer literature.

Limited communication both within the family, and with the outside community is one of the pervasive findings which is expected to have a significant impact on the siblings' level of anxiety and feeling of isolation.

In several studies children appear to be poorly informed about their siblings' illness. In Burton's study of 58 families of children who have cystic fibrosis, 53% of mothers had never discussed the disease with the sick

child's siblings. Explanations given to the remaining ⁴⁷ 47% were simplistic and minimal. In the same vein, it seems that healthy children rarely ask questions about the disease or its treatment. Burton interpreted this to be a reflection of the children's need to protect their parents. The children fear that the parents lack the capacity to tolerate the illness and that their questions may precipitate a breakdown or a rejection of themselves. Thus siblings avoid loss of contact and maintain the approval of significant adults by keeping their thoughts and feelings to themselves.⁶⁷ Further supporting this interpretation, Meyerowitz and Kaplan found that children who were aware of their siblings' diagnosis of cystic fibrosis were a source of significant stress to their parents. Apparently, family discourse about the illness may precipitate overwhelming parental emotions of sorrow, anger and fear of loss of control.⁶⁸

The siblings' situation is further complicated by the fact that the illness of one child alters the family's relationships; with the broader community both quantitatively and qualitatively. The relative isolation of such families has been described in a number of studies.⁶⁹

The healthy children in such families are not only aware of this isolation, which deprives them of vital social opportunities and supports, but are also aware of their responsibility to protect the family's image.

Voysey's brilliant paper on impression management vividly describes how the parents of sick children strive to project an image of normalcy to others by carefully controlling illness-related information.⁷⁰ Since the healthy siblings are often expected to act as informers, when unsupervised in public, parents commonly fear, that the siblings will give the game away by revealing too much to neighbors, relatives, teachers, or peers. The burden of this conflict and the challenge of withholding information without alienating significant others, must be a source of both anxiety and isolation for the healthy siblings. These feelings are further exacerbated by the limited flow of information within the family. Cadarang et al. postulated that within the families of diabetic children the natural flow of information about the illness is blocked by the mothers' coping pattern often characterized by denial. Healthy children, troubled by illness related information deficits feel further isolated and excluded from a major family problem.⁷¹

Turk in his study of families of children with cystic fibrosis also observed that this pattern of diminished communication spreads to other aspects of family life, producing a generalized "web of silence".⁷²

Another phenomenon which was noted in many articles related to the central role the disease assumes in forming the family's way of life. One child's health problem may directly influence where the family will live. Families

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often move to be closer to a treatment center or to find a better climate for the sick child. Moving involves both financial, social and psychological costs that clearly affect the healthy siblings. Several studies document that parents must also channel a disproportionate amount of their financial and emotional resources into the care of their sick child.⁷³

The healthy children, may be intellectually able in some circumstances to understand that such a disproportionate allocation of resources is necessitated by their siblings' illness, but given their lack of adequate information about that illness, it is unlikely that they can emotionally accept their own displacement and deprivation without paying a serious price in their own emotional growth and perception of themselves as important people worthy of their share of family resources and commitments.

This phenomenon may explain the many references made to the negative self image of normal siblings in studies dealing with such disparate health problems as kidney disease, downs syndrome, leukemia and cystic fibrosis.⁷⁴

Susan Klein's research on the siblings of renal patients involved face to face interviews with 72 children who had the disease and 44 siblings who were close in age to the patient, as well as 65 mothers.

When siblings were asked a number of questions about their feelings about their sick sibling's illness, they

most frequently answered that they were frightened.

Klein also found that although siblings reported that they had a lot of extra chores in helping to care for the sick child, they often did not resent this, if they were helped to understand the sick child's needs.⁷⁵

Illness-related communication, emerges from all these studies as a significant variable to be addressed.

III. SIBLINGS OF THE RETARDED

It is in the field of retardation that the impact of a child's physical or mental handicap on his siblings was first recognized.

Professionals in this field of specialty have remained in the forefront in recognizing and highlighting the needs of siblings.

One of the earliest and most extensive studies of the effects of a severely mentally retarded child on family integration and on sibling functioning was conducted by Bernard Farber in 1959. In the investigation, 240 families living in the Chicago metropolitan area with a mentally retarded child 16 years and under were interviewed. 175 of these families had the mentally retarded child living at home and 65 families had their child living in an institution.

When Farber compared sibling relationships, the following conclusions were drawn:

Normal brothers and sisters manifested more

personality problems when the retarded sibling was at home than when he was in an institution. On the average, the normal sister was helped by placing the retarded child in an institution.

Institutionalizing the retarded child did not seem to help normal brothers. The brothers were slightly higher in adjustment than their sisters in families with a retarded child at home. However, when normal brothers and sisters of institutionalized children were compared, the maladjustment of brothers was generally greater than that of sisters. Farber concluded from his findings that differences in sex roles must be taken into account in assessing the effects of a retarded child on his family. He interpreted his findings to mean that placing the retarded child in an institution seemed to expand the normal brother's role in the home, creating many additional points of stress between the normal boy and his mother.

The sister who had been delegated duties concerning the retarded child was relieved of many of these responsibilities by the removal of the retarded child from home. Her family role was hence contracted and many points of conflict between mother and daughter were removed.

Farber also found that the retarded child's brothers and sister's were adversely affected by a high

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degree of dependence of the retarded child. These results suggested that the pressures of caring for the retarded child and the responsibility placed upon his siblings adversely affected the normal sibling's adjustment in relation to his mother. This interpretation was further supported by the finding that younger retarded children affected the adjustment of their siblings more than did older retarded siblings.⁷⁶

Farber's study was criticized because his sample was drawn from the mailing lists of associations promoting the welfare of the mentally retarded and therefore was not considered to be representative of a cross section of families. His reliance on volunteer participants for the study was further regarded as biasing his sample, thus subjecting it to systematic error.

In a similar study Carolyn Fowle conducted an investigation of 70 families in two rural counties in California. 35 families had a child in an institution, and 35 kept their retarded child in the family, at home. The severely mentally retarded children ranged in age from 3 to 17 years.

Fowle found that a significant number of parents reported an improvement in the behavior of the normal siblings after the retarded child has been hospitalized, decreasing sibling role tension.⁷⁷

Another study by Fotheringham, Skelton and Hoddinot

which compared the families of 90 severely retarded institutionalized children with the families of 38 severely retarded children who were living in the community matched every third institutionalized child with a child living in the community. Repeated testings yielded data which showed that the siblings of the children living in the community functioned significantly less well than the siblings of children who were institutionalized.⁷⁸

Although the studies cited above demonstrated that the presence of a severely retarded child in the home created severe stress and interpersonal conflict for siblings and parents, not all studies yielded the same results.

Graliker, Fishler and Koch (1962) upon interviewing 21 teenage siblings of retarded children concluded that the presence of a young retarded child at home did not have an adverse effect upon the teenagers.⁷⁹ Bernard's comparative study of fifty families of severely mentally retarded children with fifty families of non-handicapped children also yielded data which showed no significant differences between the sibling role tension scores of the two groups. Bernard interpreted this finding as evidence that the siblings of mentally retarded children adapt themselves to the reality of the child's retardation and are not adversely affected by his presence.⁸⁰

Gath compared the frequency of psychiatric disorder of brothers and sisters of Down's Syndrome children

influenced by sex differences and found that the negative effects of having a mentally retarded sibling were more extensive with the sisters of the retarded child.

"Disturbances in the boys, known to be significantly more frequent than in controls, was related to family size and social class. Disturbances in the girls known to be more frequent than in controls were related to the type of school, birth order and age in relation to Down's Syndrome child.⁸¹

Miller concluded her exploratory investigation of 35 families whose retarded child was between seven and 18 years old, and had at least one normal sibling aged seven to eighteen, with the observation that the effect of a retarded child on normal siblings can be either positive or negative. She found that normal siblings tended to engage in more activities of an instrumental nature with their retarded sibling while they participated in more expressive activities with their normal siblings. When analyzing perceptions of parental norms, Miller also noted that the normal sibling felt it was more permissible to express negative feelings towards their normal sibling than toward their retarded sibling.⁸²

Other authors are much more assertive in stating that the siblings of the retarded constitute a population at risk for emotional disturbance. Martino and Newman, in a widely distributed monograph on the siblings of the retarded claim that siblings of the retarded constitute an

identifiable group who are overrepresented in child psychiatry clinics. They present several poignant case vignettes drawn from clinical records and observe that a major underlying symptom in this group of clinic patients is guilt. Their interpretation of the cause of the guilt and anxiety observed is insightful and fascinating, but their monograph lacks any numerical substantiation for their observations and claims. Their sweeping statements about the prevalence of problems among siblings of the retarded, therefore lack credibility.⁸³

Other practitioners who have encountered siblings of the retarded in their clinical work, have attempted to use their observation as a basis for prevention intervention.

Schreiber and Feeley who pioneered sibling groups with an experimental group of 10 siblings reported:

"Our experience suggest that the young person with positive family relationships is often capable of enduring the emotional hurt and anxiety of having a retarded sibling without severe disruption of his family and social life. He needs reassurance and support but more often his primary requirements are educational. The more clearly normal siblings of the retarded can see the realities of their particular situation, the better position they are in to cope with them."⁸⁴ Other sibling groups for preschoolers as well as adolescents are reported in the literature.⁸⁵

In recent years, sibling groups have been actively sponsored by the Association of Help For Retarded Children. Siblings of the retarded and the developmentally disabled have also benefited from the establishment of a nationwide sibling network. The value of sibling groups is most succinctly explicated by Cleveland and Miller.

"Parent groups and sibling groups can be effective in providing a milieu for families to admit their fears and hopes in a supportive setting, to gain added insight into their total family relationships and to learn specific techniques for handling problems which arise within the family and from the outside."⁸⁶

At two national conferences on issues dealing with the siblings of the retarded sponsored by AHRC in 1983 and 1984, siblings who participated at the conference asked for interventions beyond sibling groups.

A panel of siblings recommended that the normal siblings of the retarded should be included in the psychosocial services offered to the retarded child and his parents from the time of diagnosis.

"A Sibling Manifesto" developed by "Siblings for Change" reveals, upon careful reading, the many concerns and anxieties which accompany the sibling role.⁸⁷

Paramount among the older siblings' concerns, is their emotional, financial and legal responsibility for

their retarded or developmentally disabled sibling once their parents die. Older siblings have become an energetic action group, lobbying for the kind of resource development and legislation that will enable them to fulfill this complex role, without sacrificing their own lives and needs in the process.

IV. SOCIOLOGICAL AND PSYCHOLOGICAL STUDIES AND THEORIES

Sociologists of the family have studied general aspects of the sibling phenomenon and have found that there are gender differences in the way sisters and brothers structure their relationships. Sociability and solidarity have been seen as characterizing certain stages of life.

Psychologists Bank and Kahn, in their critical analysis of sociological work on siblings point out that due to the sociologists' reliance on the interview method with large groups of individuals, "sociologists often fail to portray the rich details of people's lives".⁸⁸

Normal relationships between children in the same family possess certain unique and important features. Bank and Kahn's criticism notwithstanding, the essence of sibling relationships has been very meaningfully described by two sociologists, Bossard and Boll in their book on child development.

"One of the distinguished features of the relationship between siblings is their inclusive character.... Children in the same family may play together, work together, be together for long periods of time...for a day, a week, a year. Sibling quarreling goes on between two personalities who are forced to

spend long hours together.

The second aspect of the inclusiveness of sibling relationships is the range of contacts included. Depending upon circumstances, children in the same family eat together, share the same room, play together, play with the same toys, wear each others' clothes.... Relationships between siblings permit little or no dissembling. In the parlance of the baseball world, each solves the delivery of the other early in the game.

No tricks will suffice, no deception will work. Siblings come to know each other like a book. They come to live largely with each other with their hair down. Parents and other adults are less satisfactory companions than are others more like equals. Living with other children in the home from the earliest days fosters an abiding appreciation of the rights of others. This appreciation comes in large measure through conflict."⁸⁹

The above quotation illustrates the unique, all inclusive nature of the sibling relationship. Role theory provides an additional dimension when one acknowledges the important role siblings play in each others' lives. Siblings as teachers, socializers, protectors, rivals, allies, advocates, inhibitors, have been described in various studies, most notably in Minuchin's work with families in the slums.⁹⁰

A recent book by two psychologists provides the most comprehensive exploration of sibling relationships and offers a beginning theory to explain the ways in which siblings attach, create each others identities and affect the course of each others' lives. Bank and Kahn used participation observation over an eight year period to

study the sibling bond in their own practice as individual and family therapists.

Most of the 250 high interest sibling situations accumulated for careful study came from their own patients and colleagues who requested consultation for their patients. They followed leads wherever they could find them, interviewing people who were not patients but whose sibling relationship appeared unusual or interesting. They obtained volunteers from a variety of settings, college campuses, professional organizations and social service agencies. The siblings studied were of all ages and different social classes, ethnic origins and life experiences. Approximately 1/5th of the interviews were conducted in people's homes, and nearly 100 interviews were videotaped and audiotaped to permit detailed analysis.

The authors emphasize that they tried to enter the lives of siblings, discovering the innermost feelings of brothers and sisters in their own terms. As a result of their work, Bank and Kahn conceptualized the sibling bond as follows:

"The sibling bond is a connection between the selves at both the intimate and public levels. Of two siblings; it is a fitting together of two people's identities. The bond is sometimes warm and positive but may also be negative...Through the sibling relationship one gets the sense of both being a distinct individual and of constancy through knowing the sibling as a predictable person. Even when the relationship is uncomfortable brothers and sisters derive a sense of comfort from a familiar presence."

Bank and Kahn coined a new concept, "sibling access" which they view as the key component which determines siblings' emotional dependence on each other. Similarity in age promotes access to common life events. While differences in age and sex diminishes access. Identical twins represent the most extreme cases of high access which denotes the greatest emotional dependence between siblings. This conceptualization helps to explain the finding of so many studies that siblings who had a sick or handicapped child similar in age show the greatest degree of emotional disturbance.

Since Bank and Kahn regard the sibling relationship as a central force in a child's emotional and social life, they devote an entire chapter of their book to siblings as survivors, calling for psychotherapeutic interventions to assist surviving siblings to face the death of a brother or sister. They are perscriptive and clear in their recommendations.

Hospital based social workers are urged to help parents to support the healthy siblings more honestly and effectively during a child's terminal illness or sudden death. The entire professional community must communicate about these siblings who are seen at risk for psychosomatic and emotional difficulties. The authors urge hospital personnel to perform vigorous post death follow up contacts with siblings and parents, to reach out to the siblings'

schools to achieve a sensitive handling of social and academic problems.⁹²

IMPLICATIONS OF THE LITERATURE REVIEW

The literature reviewed confirmed the need for the development of a family-centered model for pediatric medical care, a model which includes siblings.

The literature review also led to the formulation of three assumptions which influenced the design and content of the project.

These assumptions are as follows:

1. The emotional, social and financial impact of having a sibling diagnosed as having cancer, causes special stress for the well siblings in the family.
2. Including the well siblings in the medical and psychosocial services offered to the sick child and his parents will reduce some of these stresses.
3. A structured program of group support will enable the siblings to feel less isolated and to cope more effectively with the stressful role of the well sibling.

Specifically, the siblings' feelings of anxiety and isolation described in the pediatric cancer literature were selected for exploration and intervention in the study, because they could be addressed by professionals without

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adding undue burdens to the already overburdened parents.

Anxiety and isolation have also been selected for study because of their potential disabling effects on the healthy siblings' psychosexual and personality development.

There is cumulative evidence in the psychiatric literature indicating that anxiety can lead to psychosomatic illness, behavioral problems, learning difficulties and psychopathology.⁹³

Anna Freud describes the casual relationship between anxiety and neurosis in the following quotation.

"In the formation of neurosis it seems to be a matter of indifference to what the anxiety relates. The crucial point is that whether it be dread of the outside world or dread of the superego, it is the anxiety which sets the defensive process going."⁹⁴

The most comprehensive review on the subject of anxiety from the philosophical, biological and cultural viewpoints has been written by Rollo May. He has compared the different schools of psychology for their contribution to the understanding of anxiety and detailed the evolution of Freud's concepts of the meaning of anxiety. He has concluded that anxiety expresses the innate capacity of the neurophysiological organism to react to threats. The separation from the mother is the primary pattern of an anxiety creating situations. Extreme anxiety may threaten the self hood since the security which makes it possible for the individual to experience himself in the world is

threatened. However, the development of the personality of the individual is promoted by the mastery of anxiety.⁹⁵

The consequences of isolation and loneliness are less thoroughly explored in the literature although the importance of attachment to family figures, and the importance of social relationships throughout the life cycle have been documented.

Bowlby, Freud, Mahler, Spitz and others have laid the foundations for our understanding of the importance of children's attachment to parental figures as the basis of trusting and constructive human relationships.

Newman & Newman highlight the importance of social relationships in the normal development of individuals throughout the life cycle.

"Social development involves the changing nature of an individual's involvement with other individuals and with groups of people. The tasks of childhood provide the skills and context for expanded social relationships. Through play children build friendships and become increasingly intimate and diverse with age.

During middle school age, it is not uncommon to find children paired in "best friend" dyads.

In early adolescence friendships take place within the context of the more structured peer group. As friendships are made and dissolved, children learn the social skills of sharing, compromise, empathy and trust that permit them to engage in more lasting relationships during adulthood.⁹⁶

It would appear based on this theoretical

perspective that children's perceived or actual isolation from family members and peers can lead to serious disruption in their adequate emotional and social development.

Given the mental health professions' knowledge of the disabling effects of anxiety and isolation, there is an imperative to find ways to alleviate these two emotional conditions in the siblings of cancer patients who suffer from them.

Petti concludes his study of childhood depression with the following comments:

"The advances to date concerning awareness of depressive disorders in young children, determining their frequency, understanding their presentation and nature in special groups of children, tearing apart their root causes and contributing factors and developing more efficacious approaches to prevention and treatment should continue. In a period of dwindling resources for research and direct services, the creative capacities of the people working with young children will be stressed and tested repeatedly."⁹⁷

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CHAPTER II
METHODOLOGY

CHAPTER OUTLINE

- A. INTRODUCTION
- B. PURPOSE OF THE RESEARCH
- C. NATURE OF INTERVENTION
- D. EVALUATION FRAMEWORK
- E. HISTORY OF THE PROJECT
 - 1. Selection of the Site for the Project
 - 2. Description of the Site
 - 3. Program Initiation
 - 4. Overcoming Organizational Obstacles
 - 5. Program Contact
 - 6. Implementation
- F. INSTRUMENTS

CHAPTER II

METHODOLOGY

A. INTRODUCTION

This chapter describes the history and methodology of the project. It explains the nature and purpose of the research and describes the organizational and clinical factors and considerations which influenced the research design. The selection of the site for the implementation of the project is explained and described the complex process of implementation is depicted. The nature of the setting as well as the characteristics of the sample groups are described. Finally, the range of methods for data collection, monitoring and evaluation are documented and discussed.

B. PURPOSE OF THE RESEARCH

This exploratory study was undertaken to provide information about the unmet psychosocial needs of the siblings of pediatric cancer patients and to provide information about ways in which their needs can be met.

Although well siblings of children with life threatening illness such as cancer have been recognized by many practitioners and researchers as a high risk group in need of intervention, (Chapter I). No systematic study to date has addressed the questions of what these siblings need for their appropriate psychosocial development, and

how their needs can be met. This exploratory study sought answers to both of these questions. Anxiety and social isolation have been identified in previous studies as two important conditions from which well siblings frequently suffer.¹ These two variables were selected for exploration because they could be addressed by the professionals who work with the sick child without imposing additional burdens on the already overburdened parents.

C. NATURE OF INTERVENTION

The project employed two modes of intervention based on the assumptions outlined in Chapter I. One was a family centered treatment model in which the well siblings of a small sample of families were included in the diagnostic and treatment process of the cancerous child (Model I). The second mode of intervention was a support group developed specifically for the siblings (Model II).

The project examined which mode of intervention provided the most effective means for assessing and meeting the psychosocial needs of siblings.

D. EVALUATION FRAMEWORK

As suggested by Carter and Wharf, the most appropriate evaluation framework for a model program at such an initial stage and with a high degree of change and instability is not an outcome evaluation but a formative process evaluation which serves to refine the program

through frequent communication and feedback. Descriptive monitoring research, intended to describe what occurred rather than to explain it, was most appropriate for this project which sought "to collect information about a problem, a group or an organization and to explore issues that occur in implementing new strategies."²

In order to obtain data for a formative monitoring system records of various kinds were maintained. A precise diary was kept by the investigator throughout the implementation of the project. This diary was the source of the descriptive material in the sections which follow. Several researchers have recommended the use of a diary or log of events for recording field notes.³

E. HISTORY OF THE PROJECT

The investigator holds an administrative position at Hampton Medical Center, a major teaching hospital located in one of the five boroughs of New York City.

The investigator's position as a high level social service administrator provided access to the target population and assured a certain amount of autonomy and status in the design and implementation of the study.

Description Of The Site

Hampton Medical Center is a large teaching hospital with 690 beds, 65 outpatient clinics and a close affiliation with a local College of Medicine. The Medical

Center serves a heterogenous population drawn from the five boroughs of New York City and suburban Westchester County.

The Departments of Pediatrics and Social Service have an established tradition of research and innovation coupled with a progressive philosophy of psychosocial care for patients and families.

The Department of Pediatrics has already sponsored research which led to the development of an "Impact on Family Scale" designed to quantify the impact of childhood illness on the family.⁴ The Social Service Department has developed and operated numerous patient and family groups throughout the hospital, and was philosophically committed to meeting the needs of all family members.

Consequently, this study was compatible with the traditions and interests of both departments.

Within the Department of Pediatrics, the Division of Pediatric Hematology Oncology was identified as the appropriate Division in which the study would be implemented.

This division, henceforth abbreviated to pediatric oncology, provides physician services and training at three different sites which comprise the medical center. For practical reasons, the Moses Division of the Medical Center was selected as the site for the project.

At this site alone, a total of 85 pediatric cancer patients were followed in 1981. 87 such patients were followed in 1982, and 86 were followed in 1983. Thus it

was certain the site had a sufficiently large population of pediatric cancer patients whose siblings could constitute one or more sample groups for this exploratory study.

Program Initiation and Development

The implementation of the project was initiated after a careful analysis of organizational resistance, as recommended by Rino Patti and others.⁵ Brager and Holloway's concepts of "critical actors" were used to decide whose commitment to the project had to be secured in order for the project to proceed. "For any change effort there is an individual or group of individuals who must support the effort in order for it to become a reality. In any organization the critical actors for a particular change effort will shift depending on the change being considered."⁶ For this project, the Chairpersons of Pediatrics and Social Service were viewed as the first set of critical actors.

After the site was selected and official approval of the heads of Social Service and Pediatrics was secured, the investigator began a series of planning meetings with key personnel in the Division of Pediatric Oncology and the Social Service Department.

The two pediatric oncologists in charge of the pediatric oncology Division were approached first. "For a psychosocial program to succeed in a medical setting, it must have the support of the medical staff."⁷

These early meetings which sought to specify program objectives and develop the procedures and working relationships required for the program's success constituted the initiation activities that are viewed as the first stage on program development according to the conceptual framework described by Tripodi, Epstein and Fellin.⁸

The reactions and concerns of key staff members will be summarized here since they had a strong influence on the research design. The pediatric oncology administration was not opposed to the idea of working with siblings. They did not believe, however, that anyone would have the time to do it.

The pediatric oncology program at the Moses Division is staffed by two pediatric oncologists, one fellow, one social worker, one part time psychologist, three nurses, and one nurse oncologist. This team follows every cancer patient in the clinic and on the inpatient service when the child is admitted to the hospital. The same team is also responsible for a large population of sickle cell patients served by the Division. The health care team, already stretched to its limit was understandably hesitant to take on a new challenge. The team was also fearful of encountering parental resistance, and ambivalent about the project's implications for parents. As one nurse stated: "The mothers who bring their children to this clinic already have more than they can handle with their sick

child. Is it fair to ask them to worry about their healthy children too?"

There was another factor which contributed to the professional ambivalence. In the past, individual health care team members were always willing to see siblings if the parents asked for it, or if they brought the siblings to the clinic. Although this did not happen too often, some pediatric oncology personnel had the impression that they were already helping siblings.

The ambivalence notwithstanding, the pediatric oncology and social service leadership was genuinely interested in a systematic examination of sibling needs and in the development of a sibling group.

The social work supervisor in pediatrics was an enthusiastic advocate of the project and played a major role in its development and ultimate success.

The planning meetings led to certain agreements. The condition for undertaking the study in the Pediatric Oncology Division was the investigator's assumption of the role of social worker for those families who were to be included in the study.

The reasons for this condition were twofold:

1. To establish the investigator's credibility as a social worker and researcher who would understand the pressures the health care team faced.
2. To protect the already overloaded oncology

social worker from additional responsibilities for data collection and service provision to an extended population.

This condition for the study imposed certain constraints on the project since it limited the number of families who could be studied in depth. It also added a further dimension to the complex role of participant-observer, researcher.

On the other hand, the condition provided the investigator with the opportunity to collect all data first hand and to experience the demands, conflicts and dilemmas health professionals might face in their attempts to assess and meet the needs of well siblings in their every day work.

For these reasons, the investigator accepted the dual role of case worker-researcher for the implementation of Model I of the project.

Overcoming Organizational Obstacles

Once the full interest and cooperation of the pediatric oncology leadership and personnel was secured and key procedures for the project's operation were established, the investigator proceeded to tackle the most impersonal yet potentially most formidable organizational obstacle, the Medical Center's Research Committee and Institutional Research Board (IRB).

The function of these two committees is to help the Medical Center comply with federal law PL-93-48 which

requires determination of risk and review of informed consent for all research involving human subjects. A subject is considered to be at risk if he may be exposed to harm or the possibility of harm whether physical, psychological, sociological or other as a consequence of activity which goes beyond the application of those established methods necessary to meet his needs.⁹

The consent form devised for the siblings' parents (see appendix) incorporates the kind of information which assures the IRB that ethical standards in the research will be observed and that the welfare of subjects will be protected.

The parent consent form satisfied both committees. The Research Committee was not very interested in the study but expressed only one serious reservation before approving it. Their primary concern was: "Is it appropriate to conduct research on subjects, namely siblings, who are not registered patients of the Medical Center?" Once the investigator learned that this concern was in part responsible for the Committee's delay in approving the project, she mobilized considerable informal support inside the organization and was able to convey the following rationale to both Committees.

This reservation was finally laid to rest after the investigator mobilized a lot of informal support and was able to convey the following rationale to both Committees.

Because illness affects the entire family of a

patient, social workers and other mental health professionals regard the sick person and his or her entire family as the patient, or client for their services. Family centered research which includes siblings is therefore consistent with professional social work goals and standards.

Three months after the initial submission of the research proposal for review, approval was granted by both Committees, without any requests for modification. The strategies used for gaining organizational sanction for the project are discussed in detail in Chapter VIII.

The passage of this research proposal through the approval process was relatively smooth and swift when compared with the experience of other non-medical research efforts which have been reported in the literature.¹⁰

Program Contact

While the research proposal was winding its way through the institutional approval process, the investigator was spending large blocks of time in the pediatric oncology clinic. Informal relationships with staff and parents were developed and discussions about the best way of reaching the sibling population were initiated. The information gathered in this manner was incorporated into the investigator's thinking and planning.

By the time the final approval for the for the study was obtained, the investigator had become a familiar and

accepted figure in the clinic. This was a necessary development in view of the fact that staff and the parents would eventually be approached about their well children's participation.

The clinic is a small intense world of its own in which trust and familiarity are crucial elements. Patients and parents need to trust the health care team whose knowledge, skill and concern they often perceive as their best defense against the life threatening illness they face.

Program Implementation

Model I

According to the criteria and agreements developed during the previous stages of program development, the investigator began to deliver the family-centered intervention to a small sample of families on 9/22/83.

Selection of the sample was based on the following criteria:

1. The sick child or adolescent was brought to the Hampton Medical Center for a diagnostic workup of suspected cancer, (leukemia or solid tumor cancer) after September 19, 1983.
2. There was at least one sibling aged 3 or older living in the household.
3. There was at least one English speaking parent in the family.

4. The parents intended to secure treatment for their sick child at the Hampton Medical Center after the diagnosis was confirmed.

The process followed in the implementation of Model I is summarized below:

At Hampton Medical Center, the course of every pediatric cancer patients' diagnosis and treatment follows a certain pattern although there are significant individual variations in the length and frequency of hospital stays, type of medical treatment required, and in the patient's reaction to the treatment.

The typical pattern for every patient can be described as follows:

The patient suspected of having some type of cancer is admitted to the hospital's pediatric or adolescent ward for a complete workup generally lasting two weeks.

This is a very traumatic period for the entire family involving separations, and much uncertainty and anxiety for the patient, parents and siblings whose family routine is totally disrupted. Most mothers stay at the hospital day and night during this early period.

Once the diagnosis is medically confirmed, the pediatric oncologist discusses the diagnosis, its implications and the proposed treatment first with

the parents, then the patient. This order is important since parents must consent to the treatment and must also permit the physician to share the correct diagnosis with the child or adolescent. Both parents and the child are given ample opportunity to think, ask questions and express fears and concerns.

For the families in Model I of the study, the investigator was included in all the meetings with the parents and the patient. The investigator was introduced as the family's social worker who was interested in helping every member of the family during the patient's contacts with the hospital and the clinic.

The investigator also conducted several separate interviews with both patients and parents. In these interviews information was gathered about the entire family with special focus on the well siblings. The information was collected in a diary described in the section on instruments.

Parents were encouraged to include siblings in the hospital experience and the investigator met with the siblings as frequently as possible.

After the patient was discharged from the hospital, the investigator continued to function as the family's social worker meeting with the patient and family during clinic visits and subsequent

hospitalizations, if they occurred.

This enabled the investigator to observe and record the events and changes which affected the siblings during the various phases of the child's illness. It also enabled the investigator to assess the well siblings psychosocial needs during these various phases, and to help the parents and health care professionals meet these needs as much as possible.

Sample Studied in Model I

Convenience sampling was used to select three families to be studied in depth using the family-centered model. The families were selected to yield the greatest variation in sibling ages, patient diagnosis, anticipated treatment course and anticipated parental reactions to the illness. Minority families were given preference for two reasons:

1. They constituted the majority of the clinic population at the time of the study.
2. Their needs have been most ignored in the literature.

The investigator's comprehensive literature review did not reveal any references to minority families whose healthy siblings can be expected to be at greatest risk for

emotional and social neglect due to the families' limited financial and social resources. The correlation between minority status and limited social and economic resources have been well established.

Family A

The patient was a black 4 year old fraternal twin who was diagnosed to have acute lymphoblastic leukemia. Medically he was considered in the high risk category, with poor prognosis. His treatment complications were very severe requiring frequent lengthy hospitalizations.

Patient was born in Central America. His family consisted of his parents, fraternal twin brother and an older brother aged 7. The parents did not complete high school and had a marginal income, which qualified them for certain public benefits. Mother never worked. Father was employed as an electrician's assistant. The parents had no friends and few social supports. The father's relatives isolated themselves from the patient and his immediate family as soon as the diagnosis was made.

Family B

Patient was a 15 year old U.S. born hispanic high school student whose parents came from Puerto Rico. Her diagnosis was acute lymphoblastic leukemia. The family consisted of parents (aged 40 and 45), an older sister 19, and younger brother 12, all living at home. The parents

were high school graduates and owned a small business with an income of \$30,000 a year. Mother worked in the business. The family had many friends, relatives and social supports in the neighborhood. Patient responded well treatment and was able to resume her normal functioning (school) after the first 6 months of treatment.

Family C

Patient was a 14 year old U.S. born black male whose parents were also U.S. born. Patient's diagnosis was chronic myelogenous leukemia. The family consisted of his parents, four siblings aged 12, 10, 6, 1 and a 22 year old half sister from mother's previous marriage. Parents were high school graduates and mother who worked as a secretary was taking college courses at night. Father held two jobs and the family's income was \$20,000. The mother had many friends and three relatives. The patient responded well to treatment, but his type of cancer called for a bone marrow transplant to prevent fatal complications. The siblings were tested as potential donors and two of the siblings were found to have the right type of blood to be bone marrow donors.

Although the sample was small, the rich cultural variations, socioeconomic differences and differences in the ages of the patients and their siblings, provided the investigator with an opportunity to explore the impact of culture, age and socioeconomic status on a family's ability

to meet their well children's needs.

The size of the sample was limited to three since process evaluation conducted throughout the program revealed that the dual role of social worker and investigator was so emotionally overwhelming and time consuming that using a larger sample would have jeopardized the investigator's ability to implement the second model under study, (the support group for siblings).

Implementation of Model II

The data collected on the ages of siblings of patients attending the clinic at the time the study was conducted indicated that there was a pool of siblings which could yield siblings for two homogeneous sibling groups. One group for elementary school age siblings, aged 8 - 12, and one for a teenage young adult group aged 14 - 22.

The following activities were undertaken prior to the first session of each group:

The investigator contacted the parents of each sibling in person, or over the phone. The purpose of the group was explained to them and their questions and reactions were solicited and recorded. Parents were given the consent form, either in English or in Spanish and were given the opportunity to discuss the group with their spouses and their well children prior to signing the consent form. Those parents who felt that their children would be anxious or ambivalent about coming to such

a group were encouraged to make an appointment for their well child to meet the investigator so that their anxiety could be explored and alleviated.

The parents' reactions and the information obtained from the siblings directly was used to maximize the acceptability and effectiveness of the program. For example, one 9 year old sibling who decided not to join the group was extremely upset during the interview at the thought that the meeting would be held in the clinic area, a place he associated with his sick brother's pain and deterioration. Feedback from parents also suggested that a physical area which was close to a place they knew and could easily find, yet was somewhat divorced from the treatment area, would be more acceptable to the siblings. The investigator, therefore, secured the clinic director's spacious office for the younger group and a spacious conference room for the teenage group. The parents' opinions about the best day and time for the meetings were also incorporated into the actual scheduling of the program since the investigator sought to reduce parental resistance and give parents a sense of participation and control in a new program which they welcomed with considerable anxiety.

In order to collect data about the siblings and convey recognition of the status of parents as people who know their healthy children best, parents were asked to complete the CAAP questionnaire on their healthy children prior to the first group meeting. Parents cooperated

readily in completing the questionnaire which apparently counteracted their perception and fear that the investigator might jump to conclusions about their healthy children based on their performance in the group, a performance about which the parents had no control.

The actual content and operation of the sibling group program was recorded and is described in detail in Chapter III as recommended by Riecken.¹¹

Sample for Model II

For the elementary school age sibling group eleven parents and their well sibs were contacted and interviewed. Two parents declined because they lived too far from the hospital for their healthy child to attend. Two declined on the basis that their healthy child was not interested in participating. Three agreed to their child's participation but for various reasons never actually followed through. A core group of five healthy siblings participated in the eight session group.

Program Offered

The elementary school-age sibling group consisted of three boys and two girls. The ages ranged from 8 - 12. All five children were older than their sick sibling. Four of the sick children had leukemia, one had lymphoma. The average time lapsed since the sick child's diagnosis was 21 months. Two of the siblings were brothers. None of the other children had met before. Only two of the well

siblings had another sibling who was also healthy. One child had two sick siblings, the one who had leukemia, another who was autistic. All five children were of hispanic origin. Two to the children were born in the U.S., to parents who came from the Dominican Republic and Cuba. Three of the children were born in Puerto Rico. Four of the five children lived with their biological parents, one lived with his mother and stepfather.

Four of the five children were practicing Catholics, one did not belong to any church.

The mothers of all five children were full-time housewives, none worked. Four out of the five children came from families with marginal incomes which entitled them to certain public benefits.

For the teenage young adult group, ten parents were contacted and interviewed. Nine of the parents had more than one healthy child who was a potential candidate for the group by virtue of age, so that letters of invitation to the sibling group were mailed out to 18 well siblings (See appendix).

Of the ten parents contacted, only one indicated that she'd oppose her daughter's participation. This 18 year old healthy sibling already had such strained relationships with her father due to the fact that she was never home. The mother felt that giving her another reason to be away from home, even if it was "for legitimate purposes" would only contribute to further tension at

home. The other nine parents were interested in their healthy children's participation, but were concerned about transportation and conflicts with work schedules.

Seven of the siblings who were reached by phone after the written invitation was sent out indicated that they were interested in participating if they could arrange their work hours to minimize conflict.

Because of the siblings' heavy workload and home responsibilities, the teenage, young adult group program was only offered one night a week for four sessions only.

The attendance at these sessions was much more varied than the one in the younger elementary school age group.

A core group of 4 - 5 siblings attended most of the sessions. One sibling who already had a drinking problem attended only two sessions. The ages of the group members ranged from 14 - 19, with a mean age of 17. One 29 year old brother asked to join the group one week, but did not return since he felt the others in the group were too young for him.

The core group consisted of four girls and one boy. As in the younger group, two of the participants were siblings.

Culturally the teenage group was also very heterogeneous, although all the well siblings in this group were U.S. born. One girl was hispanic, with parents who came from Puerto Rico. Two of the members were Jewish and

three were Catholic. One of the members was black, two members had parents of mixed Italian-Irish heritage. With one exception, all the siblings came from middle class families. All the parents completed high school and the parents of four members of the group were college educated. Most of the mothers in this group worked and all the siblings in the group held jobs after school, or on a full-time basis, if they had already completed school. The 19 year old with the drinking problem and his 29 year old brother who attended only one session were the only participants who were not in school or at work full-time.

INSTRUMENTS USED FOR DATA COLLECTION

A variety of instruments were used for data collection. These included:

- a. Diaries
- b. Questionnaires
- c. A psychometric instrument, the CAAP scale
- d. Attendance records
- e. Interviews
- f. Tapes
- g. Observation reports

Diaries

The investigator maintained a detailed diary of all the activities and experiences which led to the

implementation of the program.

A separate diary was kept, documenting all the activities which comprised the intervention in the group program. The purpose of these diaries was to collect sufficient descriptive information which could later be used to analyze issues which occurred in implementing a new program and could also be used to replicate the program in other settings.

Questionnaires

The investigator designed two simple questionnaires, one which provided basic information about the sibling group participants, and an evaluation questionnaire which sought to collect the participants', opinions and suggestions for the program after the group program ended.

Both questionnaires contained open ended questions designed to solicit optimal information in an area in which "response categories are difficult to anticipate."¹² The questionnaires considered the age level of the participants and solicited information which was non-obtrusive and did not provoke any anxiety.

The basic questionnaire was pre-tested with four siblings and questions which sought information about feelings of isolation and anxiety directly were eliminated because they were found to be too anxiety provoking in the pre-test. The investigator, therefore, found ways to ask specific questions about isolation and anxiety in the group

program after the siblings established sufficient trust in the investigator to permit them to answer the questions without feeling threatened.

The CAAP Scale

The CAAP Scale was developed by Robert B. Ellsworth for measuring adjustment in a reliable, valid and efficient manner. The scale underwent a series of developmental phases and is currently a standardized instrument widely used in schools, mental health centers and probation department. The Scale contains 20 items that measure five adjustment actors: A) Peer Relations - gets along with others freely, invites other to play and laughs and smiles easily. B) Dependency - wants help for things could do on own, becomes discouraged when attempts things on own, asks for help when could have figured things out on own, and asks unnecessary questions instead of working on own. C) Hostility - flares up if can't have own way, becomes upset if others don't agree, picks quarrels, and not responsive to discipline. D) Productivity - works hard at tasks, stays with assignment, uses full abilities and works carefully. E) Withdrawal - sits and stares doing nothing, does things slowly, appears indifferent and uninterested and day dream. This dimension is viewed as measuring anxiety and depression. The scale is designed to be rated by parents, teachers, counselors and treatment staff who observe and work with children and adolescents. Each item

is scored and the score for each adjustment factor can be summed on the scale itself.

This standardized instrument for the measurement of child and adolescent adjustment was selected as the instrument to be completed by parents on their well children in the group program. It was selected from a number of widely used psychometric measures for two reasons.

1. The CAAP Scale items on Peer Relations, Dependency, Hostility and Withdrawal were anticipated to yield relevant information on the two variables of anxiety and isolation which the investigator sought to explore.
2. The questionnaire was easy to understand and complete and thus would not impose undue burden on parents who were already overwhelmed by the care of their sick child.

Attendance Records

Attendance was recorded at every sibling group meeting, and the reasons for non-attendance were also recorded on the same sheet.

Interviews

Interviews were the primary means for data collection in the family-centered intervention known as Model I. The interviews with the patients, their parents

and well siblings were unstructured since "This technique is best suited for studying highly sensitive or unexplored subjects in depth through the use of open-ended questions."¹³

The interviews sought to collect information primarily about relationships between patients, siblings and parents. Changes in family and peer relationships after the diagnosis and the manifestations of siblings' needs and feelings, with specific exploration of feelings of anxiety and isolation were recorded in logs maintained on every family in the sample.

Tapes

The meetings of the elementary school age sibling group were recorded. Since so much of the participants communication was non-verbal, body language, physical activity and drawing of emotions and thoughts on the blackboard, the investigator recognized that accurate detailed observation records, or logs of each meeting were also required.

In the teenage group, the tapes were eliminated altogether after three of the group participants indicated that the tape-recorder made them uncomfortable and interfered with their ability to speak freely and openly. Detailed observation records of each meeting were maintained.

The observation record, written immediately after

each session, captured highlights of the group's atmosphere, including interaction between group members as well as interaction between group members and co-leaders.

Evaluation of the two models of intervention based on data collected with these instruments is reported in Chapter IV.

Issues of Reliability and Validity

Reliability was fostered through different means in the two models implemented in the study.

In Model I, the observations of the investigator and the objective data gathered in interviews was compared with the observations and recordings of other health professionals in the Medical Center all of whom interacted with the patients, parents and siblings throughout the patient's hospitalization and outpatient treatment.

Systematic exchange of objective and subjective data helped to enhance the reliability of the investigator's findings, subject to the complex problems inherent in the investigator's role as participant observer.

In the sibling group program the presence of a co-leader who was familiar with the aims of the study and with the observation techniques used in the group, helped to reduce the bias of the investigator's observations and increased the accuracy of the investigator's recordings.

Content validity of the two models of intervention and their recording was based on the investigator's long

experience in working with families and children in the health field and in an exhaustive search of the literature, coupled with the thorough consultation of experts in the field of pediatric illness.

The Project Report

The ensuing report of this study is divided as follows:

Chapter III contains the description of the implementation of the family-centered Model I; the activities of the investigator with siblings, patients, parents and staff members during the diagnostic and treatment phases of the patients' illness and the data collection process in each phase of the illness.

Chapter IV presents the analysis of the observations derived from the family-centered Model of Intervention.

Chapter V contains the description of the Implementation of Model II, the Sibling Group Program; group composition, attendance patterns, leader activities, group process and the effects of the group program.

Chapter VI presents the findings of the group program. It focuses on the themes which emerged in the two sibling groups and analyzes the implication of these themes for practice.

Chapter VII presents the evaluation of both models of intervention by the participants: the siblings, parents, and the health care team. The sources of data for this evaluation are described, and data are presented and discussed.

Chapter VIII explores in some depth the total experience with the project. The implications for practice are reviewed and recommendations for future research and practice are enumerated. The relative merits of the two models of intervention are analyzed.

NOTES - CHAPTER II

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CHAPTER III
IMPLEMENTATION OF MODEL I: FAMILY-CENTERED INTERVENTION

CHAPTER OUTLINE

- A. INTRODUCTION**
- B. INTERVENTION AND DATA COLLECTION**
- C. WORKER ACTIVITIES: DURING THE DIAGNOSTIC PHASE AND
TREATMENT PHASE**
- D. ACTIVITIES WITH PARENTS DURING THESE PHASES**
- E. EFFECTS OF MODEL I**

CHAPTER III

IMPLEMENTATION OF MODEL I: FAMILY-CENTERED INTERVENTION

INTRODUCTION

This chapter will recount the actual operation of the family-centered model of intervention.

The principles, activities and procedures which constituted this model will be described in detail to enable the reader to understand the nature of the program, and to replicate it in other settings if replication is desired.

Kahn defines program development and implementation as the translation of a general goal into specific operation.¹ This chapter will demonstrate how the goals and objectives of the study operationalized.

Model I

The family-centered model had three objectives:

1. To explore the nature and causes of sibling anxiety and isolation through in depth study of the target population.
2. To alleviate some of the anxiety and isolation through the use of a family-centered approach of intervention.
3. To explore the feasibility and effectiveness of a family-centered approach which included the siblings of pediatric cancer patients in the

diagnostic and treatment processes of the sick child.

INTERVENTION AND DATA COLLECTION

The families selected for Model I were studied for a period of two years. This period was selected in order to permit the investigator to follow the sample families through the various phases of the patient's illness and treatment: diagnosis, induction, therapy, remission and maintenance therapy, relapse and death, or long term survival. The investigator carried the dual role of social-worker-researcher in working with these families. The reasons for this dual assignment were explained in Chapter II. The roles were complex but not conflictual. They provided easy access to all the participants, and enhanced the cooperation of the health care team. As social worker, the investigator extended direct casework services to the patients, parents and the siblings to assist them in coping with the psychological and social aspects of the illness. The investigator also provided psychosocial information to the health care team. As researcher, the investigator collected data about the family members' psychological and social functioning, their anxieties, concerns, interactions and reactions, with specific focus on their reactions to the siblings' inclusion in Model I. The investigator also facilitated the siblings' inclusion in the hospital experience by

arranging transportation, special visiting hours and the supervision of preschool siblings. The supportive activities which were designed to alleviate the siblings' anxiety and isolation were initiated by the investigator, in collaboration with team members. The specific activities of the investigator are detailed in the sections that follow.

ACTIVITIES DURING THE DIAGNOSTIC PHASE:

The investigator interviewed the patient and his or her parents within the first week of the patient's initial hospitalization for diagnostic workup of suspected cancer. The investigator also participated in the physician's meetings with the patient and parents. She was introduced the family's social worker who was interested in helping every member of the family cope with the illness during the patient's hospitalization and subsequent treatment. Parents were advised that the illness of one member of the family is known to affect every member of the family. They were also informed that the social worker, who had a special interest in the effects of the illness on siblings, would meet with the parents in order to obtain specific information about the siblings. All the parents agreed to be interviewed for that purpose. Demographic data about the entire family was recorded on an intake form included in the Appendix. These data included family composition, ages and sex of the patient and family members, marital

status, income, occupation, religion, ethnic origin, etc. In the first sibling-focused interview, additional information was secured about the ages, grades, personalities and relationships of the siblings. Historical data about the parents' relationships with all the children was also obtained. Specific information was sought about who was caring for the siblings during the hospitalization, how much they were told about the reasons for the hospitalization, and how they reacted to the experience. This information was obtained in order to supply clues to the current relationships between family members, and to provide baseline data for observations of changes in family relationships and reactions as the child's illness progressed. In order to assure comparability of data, from family to family, the recording of interviews followed the schedule reproduced in Appendix A.

After the initial interview with the investigator, and joint meetings with the physician, the parents were invited to bring their healthy children to the hospital as often as possible, and to let the siblings join the family meetings with the investigator and the physician.

All three families worked out arrangements for the siblings to visit the patient early in the hospital stay. However, they did not want the siblings included in the family meetings regarding diagnosis and treatment until they had a chance to talk to the healthy children about the

diagnosis themselves. The parents wanted to use the time with the physician to ask their own questions and to comfort their sick child who needed to cope with the frightening news about his or her illness, and its implications.

Within a matter of days during the diagnostic workup, the parents had to absorb a lot of information about the illness, the proposed treatment and its possible consequences, while they were in a state of emotional shock, a state of acute anxiety which has been amply described in the pediatric cancer literature.²

Understandably, the parents wanted to process all the information themselves, emotionally and cognitively before they decided how much of this information they would share with their healthy children. The parents' wishes were respected and they were assured that the investigator and the health care team were available to meet with the siblings as soon as the parents were ready for such a meeting. The parents were invariably ready to let the investigator meet with the siblings when they were visiting the sick child. The investigator's initial formal and informal meetings with the siblings had several purposes: 1) to gather information about the behavior, anxieties and concerns of the siblings, 2) to observe the interaction between family members, 3) to assure the siblings that they were viewed as important members of the family, who merited the interest and attention of hospital personnel, 4) to

acquaint the siblings with the physicians, nurses and social workers whose names were likely to become household words in their families as a result of the sick child's experience in the hospital and the outpatient clinic.

In one of the families studied, the sick child was diagnosed to have chronic mylogenous leukemia. This diagnosis differed from the acute leukemia of the other two sample children. The treatment of choice for chronic mylogenous leukemia is bone marrow transplantation.³ Consequently, this patient's four siblings were brought to the hospital early in the patient's stay not only to visit him, but to be tested as potential bone marrow donors. The investigator spent time with the siblings, comforting them during this frightening experience. Most children are afraid of needles and blood. For these brothers and sisters, the customary fears were intensified by their apprehension that they would be admitted to the hospital as well. The mother in this family readily agreed to have the siblings meet the entire health care team, so the siblings could gain additional information, reassurance and support.

ACTIVITIES OF THE INVESTIGATOR DURING THE PATIENT'S

TREATMENT PHASE

The investigator remained in frequent personal contact with the patient, his parents and siblings from the initial diagnostic phase, through outpatient therapy, and further hospitalizations. In the case of the family whose

sick child died, personal and telephone contacts were also maintained after the patient's death. The contacts with the siblings were both formal and informal, structured and unstructured. Previous researchers have indicated that "a high proportion of interviews in a hospital are impromptu. They occur either in the hospital, wing or in the halls."⁴ In the present study, several of the interviews were conducted in the patient's room or the outpatient clinic when the siblings accompanied the patient for his or her treatment. Several interviews were held in the investigator's office. The interviews and observations were systematically recorded on the log reproduced in Appendix A.

The investigator's activities with the siblings both during formal interviews and in meetings in the clinic included verbal interactions and play, depending on the siblings' ages. All the activities were designed to be supportive, incorporating Nelsen's conceptualization of the components of support.⁵ These components were 1) protection, which meant advocating for the siblings when necessary. 2) acceptance which was demonstrated by expressed concern and helpful responses that confirmed to the siblings that they were understood and that their feelings made sense. 3) validation, which consisted of helping the siblings maintain their self-esteem and hope, and 4) education which provided them with relevant information that helped them cope with a situation in which

they did not know what to do.

The supportive activities took many forms. For example, advocacy for the siblings included making special visiting arrangements in the intensive care unit or making sure that on a Christmas Day visit the Christmas tree on the pediatric ward had presents for the siblings, not just the patients.

An illustration of acceptance can be seen in the interview with a nineteen year old sibling who had frequent headaches and acknowledged that she was anxious about what would happen to her family if her sister died. Her fears were accepted as normal. It was also pointed out to her that her family was currently coping with the sudden crisis of her sister's illness extremely well. Thus, there was reason to believe that they could handle future crises when they arose.

Examples of supportive educational activities can be seen in the investigator's and nurses discussion with some of the siblings regarding the behavioral, mood and body changes they were observing in their sick siblings. Discussions about the appropriateness of normalizing relationships with the sick siblings were also common. "Lisa is always tired. She sleeps all the time. I am afraid to ask her for anything" lamented an eleven year old brother. He was informed that once the radiation treatments were over, Lisa's extreme sleepiness would stop and she could and should be expected to resume her role in

helping him with his homework. This sibling seemed reassured to know that Lisa's pervasive fatigue was transitory and that he would not have to treat her like a fragile doll for the rest of her life.

ACTIVITIES WITH PARENTS DURING THE DIAGNOSTIC
AND TREATMENT PHASE

The investigator's interventions with the parents can be grouped into three categories:

1. Redirecting parental attention to the needs of the siblings.
2. Facilitating the parents' ability to meet the emotional needs of siblings.
3. Providing information to siblings, parents and health professionals which could alleviate the anxiety, misconceptions and isolation the siblings were experiencing.

A case vignette for each of these categories will be offered in order to broaden the reader's understanding of the interventions.

Vignette I

One of the sample children, a five year old leukemic twin lay critically ill in the pediatric intensive care unit after a lengthy hospitalization. The investigator arranged for the father and the siblings to visit at night

in order to give the siblings a chance to see their brother before he died. The investigator stayed in the waiting room with the siblings while the parents visited alone with the sick child. When it came time to go home, both siblings, aged 5 and 6 pleaded with their mother to come home with them. The mother had not slept home during the last three months of the patient's illness. The five year old twin brother, in a typically childish move rattled a coat rack in the waiting room, out of restlessness and anxiety. The mother, already distraught and torn began to slap him unmercifully and told him to go home. The investigator intervened, telling the mother, that the siblings only wanted reassurance that she loved them too. The mother then embraced the healthy children, who clung to her with yearning, and relief, displaying both their separation anxiety and their developmental need for nurturance and affection.

Vignette II

In one of the families studied, the siblings were sent to an aunt during the initial hospitalization while mother and the sick child stayed in the hospital. Father worked daytime and visited the hospital at night. Thus the siblings were separated from the entire family and father came home to an empty house each night. Anticipating future admissions which inevitably occurred, the investigator helped the father to approach two friendly

neighbors who agreed to care for the young siblings, and take them to school during the next admission. This lessened the disruption in the siblings' lives and enabled them to have access to at least one parent who could give them, love, security and information, all of which were in short supply at a time of acute family crisis.

Vignette III

15 year old Lisa who has leukemia, came to clinic for chemotherapy, accompanied by her 19 year old sister, an overprotective companion. Lisa displayed a medium size new bruise on her right arm. The oncology fellow examined her and inquired about the history of the bruise, when it started, how, etc. Lisa jokingly admitted that she and her sister were "horsing around" and the sister threw a deodorant bottle on Lisa's bed which accidentally hit her. The sister looked visibly upset, but the physician proceeded to deliver a lecture about the need to be careful with Lisa because of her illness. The investigator intervened, explaining to the physician, that the sister was fully aware of Lisa's medical needs and was only following the team's orders to treat Lisa normally, and to expect her to clean up her side of the room, etc. The oncology fellow grasped the investigator's message and assured the sister that Lisa's bruise will not cause her any lasting harm.

Lisa's mother arrived at the clinic later and thanked the oncology fellow for reassuring the patient's sister, who has been guilt stricken over this episode since it happened.

EFFECTS OF MODEL I

The evaluation of the Model will be discussed fully in Chapter VI. This section will summarize the key observations recorded during the Implementation of Model I. The data, reported below is derived from the case records, logs and observations reports maintained throughout the Implementation of the study. 1) All the parents preferred to tell their healthy children about the cancer diagnosis, in their own way and their own time, without the presence of the health care team. They were receptive to the inclusion of the siblings in meetings with the health care team after the initial shock of the diagnosis has abated somewhat, approximately two to four weeks after the confirmation of the diagnosis. 2) The investigator's presence and interest in the healthy siblings helped to redirect some parental attention to the health children's needs. The investigator's and team's interventions enabled parents to meet these needs periodically. 3) The siblings were gratified to receive attention from the health care team. They came to the hospital willingly and shared their feelings and concerns openly.

A home visit to the family of the child in the sample who died revealed that both healthy siblings and parents benefited from the family-centered intervention. One month after the patient died, the siblings, appeared to be coping extremely well with the patient's death. Their warm affectionate response to the investigator also suggested that their association with hospital personnel was not a frightening one. This was subsequently borne out when the mother had to take the surviving twin for a routine check up. The child initially refused to go, but after the mother overcame her own anxiety, she reminded the child that he had come to the hospital many times without being hurt. He agreed to go and accepted an immunization without panicking. This finding was in marked contrast to those of Cain et al. who studied the clinical records of 58 siblings who received psychiatric treatment after the death of a sibling. The authors found that overwhelming anxiety about hospitals and medical procedures was universal for the siblings. The disturbed attitude to doctors and health workers in the population they studied prevented many of the siblings from receiving the medical care they needed.⁶ The findings related to sibling anxiety and isolation through the utilization of the family-centered approach will be discussed in Chapter IV.

NOTES - CHAPTER IIIIMPLEMENTATION OF MODEL I

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CHAPTER IV
FINDINGS: MODEL I

INTRODUCTION
DATA COLLECTION
DATA ANALYSIS
THE FINDINGS
SUMMARY

CHAPTER IV
FINDINGS: MODEL I

INTRODUCTION

This chapter will describe the findings of Model I, a family-centered treatment model in which the well siblings of a small sample of families (3) were included in the diagnostic and treatment processes of the child afflicted with cancer. Data was collected primarily about relationships between siblings, patients and parents. Changes in family and peer relationships during and after the diagnosis were studied and manifestations of sibling needs and feelings, including in-depth exploration of feelings of anxiety and isolation were recorded on every family in the sample. The families' and hospital staff's reactions to sibling involvement in this model were also recorded.

DATA COLLECTION

Data forms were constructed by the investigator in order to encode the large amount of miscellaneous data collected. These forms are reproduced in the appendix.

The investigator's interviews with parents, siblings and patients and her observations in clinic visits, hospital visits and health care team meetings constituted the sources of data. Following each meeting with the siblings, parents, patients and the health care team, full

process recordings were entered in a log by the investigator. With parents but not with children, copious notes were made during the meetings and telephone contacts, capturing whenever possible the subjects' comments verbatim. The investigator recorded not only what was said by parents, children and staff but also her clinical observations and interchanges.

DATA ANALYSIS

Content analysis was applied to the process recordings of interviews and clinic and hospital meetings with siblings, patients and parents. Quantifiable phenomena such as the patients' hospital admissions, medical procedures, surgeries, etc. were analyzed in order to identify the most frequently observed events in the lives of the three families.

Meyerowitz and Kaplan's conceptualization of the impact of illness on three levels of family adaptation was used to organize the findings into a conceptual framework. Meyerowitz and Kaplan conducted an exploratory descriptive study of the effects of a child's cystic fibrosis on the personalities of family members in ill families. The study families included 337 children. One hundred and fifty seven of these children aged 4-20 had cystic fibrosis. No demographic information is presented about the 180 siblings. Data related to familial status, functioning and reactions to the disease. Data were gathered in personal

interviews with parents. No attempt was made to interview siblings. The data analysis was based on rigorous scientific methods. Meyerowitz and Kaplan concluded that based on parental reports, the stress of the illness affected family members on the intrapsychic, intrafamilial and community level. Cystic fibrosis is a life-threatening childhood disease which is similar to childhood cancer in two key respects; its terminal nature and the enormous demands it imposes on parents in meeting the medical needs of the sick child. The conceptualizations of Meyerowitz and Kaplan were therefore considered to have great relevance for the present study.¹

Presentation of Findings

For the reader's convenience, the study families will be designated as by the letters A, B, and C. Their characteristics are described in Chapter II. The findings to be reported are qualitative and descriptive. They derive from the objective phenomena which were observed in the families who participated in the study. The findings are linked to previous theory and research. The participants' evaluation of this mode of intervention will be discussed separately in Chapter VII.

FINDINGS

This investigation sought to explore the nature and causes of anxiety and isolation in siblings of pediatric

cancer patients. The wealth of qualitative data collected in the study was analyzed in relationship to these two variables. Only those phenomena which according to psychoanalytic and developmental theories and practice research are known to be related to anxiety and isolation will be reported here. The ranking of findings in terms of their relative importance as precursors of sibling anxiety and isolation was derived from an extensive review of the literature, and consultation with experts.

Overview

The cancer diagnosis of one child in the family caused serious disruption in the lives of all the subjects who participated in the study. Separation of family members, emotional realignments in the family and constriction of social life constituted some of the stressful changes siblings confronted as a result of their brother's or sister's illness. These changes were consistent with those reported in previous studies.

I. Separations

The most striking and psychologically important finding concerned the frequent and prolonged separations the well siblings had to experience, separations primarily from the mother and the sick child. Only one patient in the three families studied had a single hospitalization during the year of the study's duration. The sick children

in two of the families studied had repeated hospitalizations, the longest one for three months, the shortest for ten days, with most admissions lasting two to four weeks. The most frequently hospitalized child in the sample, in Family A died, subjecting his two brothers including his twin to the ultimate separation. In Family C in which a 12 year old sibling became the blood marrow donor for her fifteen year old leukemic brother, the other four siblings were separated not only from their mother and sick brother, but during his longest hospitalization, lasting seven weeks, they were also separated from the donor, a favorite big sister who was hospitalized for several days with her brother, both before and after the transplant. The youngest well sibling in this family, a two year old girl, developed acute separation anxiety in response to the prolonged separation. Two other siblings, aged seven and ten attempted to master their anxiety through persistent efforts to reach their mother. The seven year old girl described her and her brother's frustration in these words: "We had a terrible time getting her. When we called Tom's room, mom was in my sister's room. When we called my sister's room, she was in Tom's room." The mother confirmed that she often missed the siblings' call. This sibling's report was therefore factually accurate. It also conveyed two siblings' anxiety and feelings of loss of control when they were separated

from their primary caretaker, and experienced a division in their family.

Other researchers have noted that frequent separations are a way of life for the siblings of cancer patients. In a carefully designed exploratory study, Kramer interviewed eleven healthy siblings of cancer patients eliciting their perceptions of how the illness experience affected their lives. Separation from the rest of the family was identified major source of stress by the majority of siblings.

Kramer pointed out that the separations were both physical and emotional. They occurred as a result of the sick child's hospitalizations, frequent clinic visits and the parents' general preoccupation with the sick child which led siblings to feel emotionally distant from their parents even during times when the sick child and mother were at home.¹ Cairns et al administered psychometric tests to 47 school aged cancer patients and their siblings in an attempt to explore the emotional impact of childhood cancer. The authors concluded that:

"the siblings' difficulties appeared to stem from the many adjustments within the family following the diagnosis of cancer. Typically, the first of these adjustments is a division in the family with mother and the sick child in the hospital and the father left to manage as best as he can with the home maintenance, job responsibilities and the care of the other children. In this situation, the siblings' need for daily attention and nurturance may receive low priority."²

The present study confirmed both Kramer's and Cairns' observations.

II. Emotional Realignment Within the Family

Changes in relationships between family members, and changes in the roles and activities they performed were observed in all the families studied. The changes were associated with parental reactions to the illness and with responses to the demands of the illness. One illustration is selected here because it captures the essence of the changes observed. In Family B, both parents felt too nervous to learn to give injections at home in order to eliminate the need for the patient's hospitalization for some of her chemotherapy. They nominated their nineteen year old daughter for the job. This sibling was also anxious, but she accepted the responsibility after some thought. The patient at first objected. "She is my sister. I don't want her to be my nurse." Three realignments occurred after 19 year old Beth (pseudonym) assumed the "nursing role". 1. Beth and the patient became extremely close. 2. The parents suddenly treated Beth as an adult, an equal whose own needs for parental assistance with the developmental tasks of vocational goal setting and separation and individuation were slighted. 3. The youngest brother in the family was left out of the new sibling subsystem.

Many researchers and theoreticians have alluded to changes in family relationships resulting from one family

member's acute or chronic illness,³ Kramer was the first author to describe in graphic terms the relationship changes some siblings of cancer patients experience. She writes: "The first source of stress for the well siblings, emotional realignment stems from parental preoccupation with the sick child. A triad forms between mother, father and ill child while the healthy siblings are left on the periphery of family life."⁴ Kramer used quotations from several siblings to illustrate how siblings' experienced the parents' favoritism towards the sick child as personal rejection and deprivation.

The present study confirmed the presence of extensive changes in familial relationships and dynamics. These changes took different forms and were influenced by several factors such as: premorbid family structure and dynamics; the ordinal position of the sick child; his response to the illness and its treatment; the parents' ability to cope with the diagnosis and the availability of extended members of the family.

One similarity was noted in all the families studied. The mother and the sick child developed a special closeness from which some or all the siblings were excluded. This special bond was initiated at the time of diagnosis. All three mothers slept at the hospital during the initial hospitalization. This behavior was consistent with the findings of other authors who have studied the families of fatally or chronically ill children

encompassing several disease entities: leukemia, cystic fibrosis, juvenile diabetes and nephrosis. Travis, a well known authority on the psychosocial impact of chronic illness in children has incorporated many of the existing studies in her book. She notes:

"A recurrent distortion of relationships in the families of chronically ill children seems to be the father's abdication of responsibility and increased absence from home. Entwined in an abnormally close relationship are child and mother. The cause in part induced by the mother's involvement in medical care while the father is working. She becomes an authority on what the doctor says and recommends and the father is gradually left out."⁵

In the present study, only one father "abdicated his responsibility" although all three mothers were entwined in an abnormally close relationship with the sick child. In other respects, the families showed considerable variation in their adaptation to the illness. In Family A the mother became totally absorbed in the patient's hospital care. She could barely be persuaded to go home to change her clothes and spend time with her husband and healthy children. In Family B the mother-sick child dyad became a triad, including the nineteen year old healthy sister who shared the mother's preoccupation with the patient, became a constant clinic companion and learned to give the sick adolescent injections at home. This arrangement excluded the father and the youngest sibling so that a once cohesive family was split in two, displacing the brother from his

role as the baby in the family, protected, and attended by everyone. A new family system developed in which the brother had no clear role. His sick sister was now functionally the baby, the center of attention and protection. Although the father stayed home with his son, his behavior indicated that his mind was on the sick child as well.

The fathers' new roles and emotional realignments showed the greatest variation in the families studied. In Family C the father withdrew completely, unable to cope with his son's illness. He remained at home with the other children but was unable and unwilling to make himself emotionally available to any family member, including the sick child. This father visited his son only once during three separate hospitalizations although he had a close affectionate relationship with him prior to the cancer diagnosis.

In Family A, during the patient's repeated hospitalizations, the father became a devoted primary caretaker of his two young sons. He met their physical and emotional needs and turned to them for support of his own emotional and social needs during his wife's absence. The experience of this family dramatically illustrates the intrafamilial challenges and disruptions healthy siblings confront. When the sick child and mother returned from the hospital, the father reestablished close relationships with both of them leaving the 4 and 6 year old siblings anxious

and bewildered. They now felt insecure in their relationships with both parents and were also confused and uncertain in their relationship with the sick child who was both physically and psychologically a different person from the brother they knew prior to his diagnosis and treatment. The situation was further complicated by the fact that the sick child expressed all his anxiety and anger about his illness in overt hostility toward his twin brother who in the patient's perception abandoned him by not joining him in the illness experience. "Where is Ronnie? Get him here. I want him in this bed. I don't want him to stay home. He has to be with me," was the patient's frequent outcry in the hospital. Thus two brothers who had been inseparable allies and playmates prior to the illness were now mortal enemies, unable to stay in the same room without crying and fighting. The healthy sibling, overwhelmed by his twin's hostility sought comfort and protection from his older brother who had replaced the sick twin as an ally and companion during the patient's extended hospitalization. This new alliance eventually enabled both healthy siblings to cope with the death of their brother without feeling totally abandoned.

"There is a dimension of family life which has to do with the time and energy, nervous and physical that the maintenance of satisfactory family relations requires."⁶

Maternal preoccupation with the overwhelming needs of the sick child made it difficult for mothers to attend

to the emotional and social needs of their healthy siblings. This observation, also reported in the work of Spinnetta et al.⁷ partly explains the third finding which emerged from Model I.

III. Constriction of the Siblings' Social Life

Social activities decreased for all the siblings in the study families after the onset of the illness. Whether mother was at the hospital with the sick child, or busy with clinic visits and other demands of the illness, e.g. securing financial assistance, she was neither physically or mentally free to encourage, plan or facilitate the siblings' social activities. The elementary and preschool siblings in the sample were dependent on their mothers for transportation, supervision and other aspects of social life. With mother unavailable, these activities became scarce or non-existent. The older siblings' activities were curtailed by the additional chores they had to assume at home as a result of the illness, and by the guilt they felt about enjoying themselves while their sick sibling was confined to the hospital, or undergoing painful treatments at the clinic.

Other disease related factors also discouraged social activities. The treatment-induced infection proneness and irritability of the sick child led several parents to discourage peer visits in the home. Group activities such as parties, movies and concerts were

medically discouraged during the active phase of the sick child's treatment.

In Family B, the 15 year old sick child and her two siblings (19 and 12) used to go out together two or three times a week to movies, bowling allies, etc. prior to the leukemic child's illness. After the onset of the disease, fatigue and lethargy caused by the disease forced the sick adolescent to lose interest in social activities. The other siblings stayed home, out of concern and sympathy.

In Family A, the mother used to take her three young sons to the park regularly to meet other children. This activity stopped as soon as one child became ill. Even during the brief periods when the sick child was home from the hospital, the mother shunned all recreational activities fearing that her sick child was too vulnerable to take the risks of falling, catching a cold, etc. The healthy siblings had to stay home in order not to make the sick child jealous or sad.

Only one mother in the sample, the one in Family C, made provisions for her healthy children's social and recreational activities. Even in that family, a long planned family trip to Canada had to be cancelled due to the sick child's treatment complications, leaving all the children in the family disappointed, without any plans for the entire summer.

In Family B, social and recreational activities began to increase both for the sick adolescent and her

healthy siblings seven months after the sick adolescent went into remission. By that time family members were less anxious about the sick girl's condition and prognosis, and they had enough energy and confidence to permit the normalization of family activities.

Several studies have reported the general constriction of social activities in the families of disabled, retarded or chronically ill children. The parents' fear of stigma has been offered as the primary cause for this phenomenon.⁸ Several studies which have focused on siblings of cancer patients have cited the siblings' feelings of isolation as a prevalent finding.⁹ No other study to date has presented such detailed evidence about the effects of one child's cancer on his siblings' social activities.

IV. Fear of the Sibling's Death

Fear of the sick child's death was a prominent finding in Model I. This was particularly striking since only one sick child in the sample came close to death during the course of the study. Two of the sick children achieved remission, without complications, early in their treatment, and were doing well medically and psychologically.

Nevertheless, eight of the nine siblings who participated in this phase of the project expressed fears about their sick sibling's possible death after the onset

of the illness. The youngest sibling in the study, a one year old girl who was developmentally incapable of understanding the concept of death, was the only participant who did not convey a fear of death either to her parents or the investigator. The siblings' fears were expressed both verbally and symbolically, in play and nightmares. "I hope that they have a Superman at that hospital. Only Superman can make you live forever," commented a ten year old sibling, the night before his brother underwent bone-marrow transplantation.

Siblings aged twelve and older not only feared their siblings' death, they also feared the effects of such a death on the integrity of the family. "I worry about how we would react if Lisa died" was a typical comment by a nineteen year old sister who coped with her fears by calling home several times a day to make sure that the patient was alright.

The older siblings' fear of the consequences of death was consistent with their greater developmental capacity for abstraction and anticipation, as described by Ericson and Piaget.

Four previous studies lend support to the finding of a prevalent fear of death in siblings. In Kramer's exploratory study, eight of the eleven children interviewed expressed fears about their sibling's death.¹⁰

Koocher et al studied 121 former cancer patients who have survived for at least 60 months after their

diagnosis. The investigators interviewed and tested 117 former patients and 101 siblings. One of the instruments administered to both patients and siblings was a Death Anxiety questionnaire. Although the siblings mean score on the Death Anxiety questionnaire was within the normal range, Koocher et al. noted with interest that the siblings' score was somewhat higher than the overall score of long term survivors, suggesting slightly greater anxiety among the siblings than the patients themselves.¹¹

Kramer did not view fear of death in siblings as a major source of stress, comparable in importance to separations and changes in parent child relationships. In the present study, fear of death appeared to be a major source of anxiety for the siblings who participated.

Overview

The cancer diagnosis and treatment of the sick child in the families studied was found to affect the healthy siblings on an intra-psychic, intrafamilial and social level. Theoretical knowledge and research evidence available from the literature provide the underpinnings for the above statement. Some of the key references will be summarized here in order to demonstrate the importance of the observations.

Separation

Research by Bowlby, Spence and others attest to the

emotional trauma caused by separation of mother and child when hospitalization of a child becomes necessary.¹² To date, only small exploratory, descriptive studies have identified the traumatic impact of separations on healthy siblings who are either boarded out to relatives during the sick child's hospitalization, or remain at home without the mother for varying periods.¹³

Indirect evidence about the intrapsychic and intrafamilial impact of separation on siblings is available from the work of Spinnetta et al. In their longitudinal, rigorously designed study of familial adaptation to childhood cancer, the investigators tested 106 cancer patients and 102 siblings between the ages of 3 - 18 using a comprehensive battery of psychological tests to assess their adaptation to the cancer experience. They found that the siblings were less adjusted than the patients on a number of criterion measures such as self-concept, communication and emotional tone. The latter measure concerned itself with "negatively-valenced affective reactions such as depression, loneliness, withdrawal and rejection."¹⁴ Specific findings in that study which are relevant to this discussion include the following: Adolescent siblings, aged 13 - 18 scored the family as significantly greater in conflict and lower in cohesion than did the patients in the same age group. In the 6 - 12 year old group, siblings scored at more maladaptive levels in items relating to anxiety and depression and in

perception of psychological distance from their parents. In the 4 - 6 year old group, siblings of cancer patients demonstrated a self concept and attitude to parental responsiveness that was significantly less adaptive than that of the patients.¹⁵ Spinnetta et al did not seek to establish a causal relationship between their findings and the incidence of illness-related separations in the study population. Their data suggest, however, that separations which stem from mothers staying in the hospital or clinic with their sick children may be a key variable in Spinnetta's findings. The present study combined with those of Kramer and Everson found that separations in families of pediatric cancer patients are often perceived by healthy siblings as abandonment and preference for the sick child.¹⁶ Both of these factors are related to self-concept and perceptions of family cohesion and emotional distance from the parents.

Separation and its impact on healthy children's psychosexual and social development has been studied by many disciplines. Over the years, clinical studies of infant development in the field of psychiatry have led the way in this area. Bowlby, a seminal theorist who published extensively on the subject of object loss, wrote in 1951: "Evidence that the deprivation of mother love during early childhood can have farreaching effect on the mental health and personal development of human beings comes from many sources."¹⁷

Bowlby, Spitz and Mahler established a vital link between a nurturing maternal presence and the development of an infant's identity. This linkage has been widely accepted by the disciplines concerned with mental health. Bowlby, Spitz and Mahler are also credited with laying the theoretical foundations for our understanding of the causal relationship between maternal deprivation and later pathology.¹⁸ The therapeutic hopelessness engendered by these early classic studies was later challenged by Prugh, Harlow and others who pointed out that only prolonged separation followed by inadequate substitute care leads to serious consequences. They stressed that the dire consequences of early maternal deprivation are neither inevitable nor universal.¹⁹

Despite these challenges, Mahler's conceptualization of the separation - individuation process as a basic process in every young child's psychological development has remained a fundamental tenet in psychoanalytic and developmental theory. In her latest book, Mahler postulated that the separation reactions of children change during the subphases of their development. She also noted that these reactions are child-specific, influenced by factors such as the presence of fathers and siblings in the child's environment. While acknowledging the importance of other family members in shaping a child's personality and behavior, Mahler views the early mother-child relationship as the primary determinant of ego and gender identity, as

well as the key determinant of children's separation anxiety and separation reactions. She writes: "These separation reaction variations depend on a host of variations in the mother-child relationship as well as the vicissitudes of the earlier subphase characteristics."²⁰ Other investigators of child development who have focused on the child's capacity to grow and adapt despite early trauma or deprivation have questioned whether Mahler's non-experimental observational studies of infants and toddlers in nurseries and toddler rooms provided sufficient empirical evidence for Mahler's theories.²¹

The classic studies of separation anxiety in infants and children have been complemented by later studies of separation anxiety in different child and adolescent populations. Freud's study of preschool children separated from their parents during World War II provided extensive evidence of depression, anxiety and agitation in children aged 2 - 4.²² Child welfare literature which addresses the impact of separation on children placed in foster care or residential care, provides additional insights. The burgeoning literature on the impact of divorce and separation on children offers considerable prescriptive data for minimizing the traumatic impact of separation or divorce.²³

Kelly and Wallerstein's studies are uniquely valuable because they were done prospectively. Children were interviewed both at the time of divorce and one year

later. The children's behavior was subdivided into logical age categories, thus providing a developmental perspective.²⁴ When the multifaceted literature on separation is reviewed, feelings of rejection and inadequacy, depression, social withdrawal, behavior changes and academic difficulties are the most frequently cited consequences of separation for children and adolescents.

There is general agreement in the literature that the following factors are related to the intrapsychic and social impact of separation on children and adolescents. Age and developmental level at the time of separation; length and cause of separation; the child's prior experience with both parents and the availability of alternate supports during the separation experience. Separation is recognized as a source of great anxiety for children in all the literature reviewed. There is universal agreement that separation activates and reactivates fears of abandonment. Strong evidence is presented, indicating that separation can evoke two kinds of behavior. "Separation from the caregiver will stimulate attachment behaviors especially efforts to find the caregiver and to regain physical contact. Separation can also evoke protest, despair or detachment depending on the length of the separation."²⁵ Both of these behaviors were observed in the siblings of the present study. Five siblings under twelve exhibited periodic clinging behavior, clinging to parents, teachers or older siblings. Two

siblings aged twelve and twenty-one withdrew from other family members during the most acute phases of the illness.

Emotional Realignment: Relationship and Role
Changes in the Family.

The family unit has been studied by representatives of several disciplines using a variety of conceptual frameworks. Among the conceptual approaches employed in such studies are those variously termed "institutional interactional" and developmental. Although these conceptual frameworks differ in emphasis and theoretical underpinnings, taken together, "they view the family group as a set of interacting personalities; a social system consisting of relating social positions (father, brother, wife, etc.) each of which is defined in terms of shared normative expectations of one position when interacting with occupants of another position."²⁶ Recent developments in the application of family theory, systems theory and family therapy have led investigators to recognize that family behavior can best be understood as a complex dynamic interaction between the personality predispositions of family members, intrafamilial role expectations and the sociocultural milieu. Minuchin is one of the most articulate and respected proponents of this view of family behavior.²⁷

Investigators and theorists who have studied the impact of illness of on families generally agree that the

illness of a family member disturbs the family's internal balance and forces patients and family members to assume new roles and relationships, resulting in family stress.²⁸

Several authors have explored the family's continued ability to meet the needs of all of its members when confronted with the stress of illness. Many families are found to devote a major share of their emotional, physical and financial resources to the care of the patient.²⁹ A much smaller number of families fail to reallocate even those family resources which are necessary for the patient's safety and care. While the literature abounds in examples of healthy adaptation on the part of families, there is no evidence that families can adapt to the experience of life threatening illness without radical shifts in roles, relationships, personalities and resource allocation.³⁰

These shifts have implications for every member of the family and place some of them at risk for emotional and physical neglect. Lansky's study of 65 infants born into 395 families who had a child diagnosed with cancer provides the most dramatic evidence of this type of risk. The study of the growth of infant siblings of children with cancer treated at The University of Kansas Medical Center was stimulated by Lansky's work with children who were treated for cancer, whose parents requested inpatient evaluation for their infants' failure to thrive.

In Lansky's survey, out of 61 families who had infant, siblings of cancer patients, 52 families completed questionnaires concerning the pregnancy and delivery the method of feeding and the growth and general health of the infant siblings. Detailed information about weight gain patterns was sought on all infants and was secured from their pediatricians. "The study revealed that among infants born to families of children with cancer, there is a striking frequency of failure to thrive."³¹ No organic causes were found to explain this phenomenon. Lansky found that for all nine babies who failed to thrive, periods of inadequate weight gain were associated with significant events or anniversaries of events, e.g. diagnosis, death relapse in the course of the patient's illness. The authors interpreted the failure to thrive of infants born into these families as a reflection of the parents' inability to care for and feed their newborn infants because of the stresses associated with cancer in another child in the family."³²

Failure to thrive in young children has long been associated with physical and emotional neglect in the field of pediatrics. Lansky's work demonstrates that infant siblings of cancer patients are at risk for physical and emotional neglect as a result of parental stress related to the illness. A corollary suggestion which emerges from their findings is that sibling age at the time of a pediatric cancer patient's illness and death is an

important factor in the type of risks the sibling faces as a result of parental stress and preoccupation with the sick child.

The work of Spinnetta, Koocher, Cairns et al also suggest that sibling age and developmental level affect the nature and severity of the impact of the cancer experience on siblings.³³

The present study confirms these findings. The preschool and elementary school age siblings who were most dependent on their parents for the satisfaction of their emotional and social needs, were the most adversely affected as were those who faced critical developmental milestones during their sibling's illness. For example, two of the children in the study had to begin first grade and prekindergarten respectively without the supportive presence of their mother who was sitting vigil at the hospital for extended periods. Not surprisingly, the school performance of these siblings was troubled. Their teachers described them as withdrawn nonverbal children who barely communicated and overreacted to any changes in the classroom, particularly teacher absence which made them anxious and hyperactive. The older sibling suffered from a severe learning disability throughout first grade which he needed to repeat.

Constriction of Social Activities

Ericson's and Piaget's developmental theories emphasize the crucial importance of peer activities and

socialization experiences during various stages of human development.

During the early school age period children shift the focus of their attention to the external environment. As children interact with peers, they become aware of the variety of perspectives that other children bring to their games. They learn to be more sensitive to others and to view the world in a less egocentric manner. The reduction of egocentrism that takes place during the early school years has implications for the development of logical thought and for the maturation of morality. During later developmental stages, children in middle school years and adolescence, accomplish critical developmental tasks in their interaction with others. The challenges of group membership and the development of a sexual identity are largely mastered through increased social interaction.³⁴

A constriction of children's opportunities to interact socially with others can impede their work on the mastery of these developmental tasks. The constriction of social activities has other consequences. Siblings are deprived of relationships with peers and other adults who potentially could offer them some of the support and recognition they need. Their ties with the community are also attenuated.

Cain and Ericson found that the availability of extrafamilial supports was an important variable in children's adjustment to their siblings' death.³⁵

Fear of Death

Healthy children's concept of death, in non-death related circumstances has been studied extensively. Nagy in her classic study talked with 378 children in Budapest during the 1930's concerning their ideas and feelings regarding death.³⁶ In 1967, Fartley and Bernasconi conducted a similar exploratory study with 60 Catholic children aged 5.5 to 6.4 years in Nova Scotia.³⁷

Adams, in his comprehensive literature review of children's concept of death noted that all researchers who studied healthy children's concept of death found that the child's concept of death evolved developmentally. Children under the age of five viewed death as being reversible and as a type of separation. Children six to nine saw death as resulting from the acts of others often as type of punishment for wrong doing or thoughts of wrong doing. Beyond the age of ten death was viewed as being personal and universal.³⁸ Several investigators have studied fatally ill children's concepts of death.

Spinnetta et al. who interviewed and tested a large sample of leukemic patients both in the hospital and in outpatient clinics also found that children's concept of death differ with age and intellectual development.⁹ In the field of childhood cancer several studies have focused on the patient's understanding of the seriousness of their illness, and on their feelings and attitudes towards death. The research evidence demonstrates that leukemic

children are aware of the possibility of their death and are frequently prohibited from expressing their feelings and fears by the overt and covert attitudes of their parents and the medical staff. Morrissey in his study of death anxiety in fifty fatally ill children concludes: "The children emphatically perceive parental anxiety and embarrassment regarding death and would endure the role playing of parents and staff experience characterized by a stoic kind of "make the best of it but let's not talk about it."⁴⁰

Although there are several professionals who hold the view that an open discussion of death with patients would overwhelm their defenses, several studies have suggested that such open communication reduces the patient's anxiety and feelings of isolation, thereby increasing his capacity to cope with the prospect of death. Share and Morrissey believe that such open communication would also enhance the coping ability of siblings.⁴¹

Adams and Benoliel offer additional reasons for addressing the siblings' fear of death. They point out that guilt and feelings of responsibility frequently accompany children's attitudes towards death. Guilt is widely recognized in psychoanalytic and mental health literature as a causal factor in the development of psychopathology.

While only one sibling in Model I openly expressed feelings of guilt about her sister's illness, stating that as the older sister, she rather than her younger sister should have developed leukemia, guilt reactions in siblings after the death of a sibling have been noted by several authors.⁴²

SUMMARY

The findings in this chapter highlight the phenomena observed in the families of three pediatric cancer patients which caused anxiety and isolation in the healthy siblings, phenomena which according to psychiatric and developmental theories constitute potential risks to the siblings' emotional and social development.

A caution is appropriate lest these findings be interpreted as an indication that the siblings in this phase of the study displayed clear cut signs of emotional impairment.

With the exception of the two siblings in Family A, all the siblings in Model I appeared to be coping with the experience of the illness remarkably well, without evidence of severe behavioral, educational or emotional problems.

Three distinct variables, idiosyncratic to Family A appeared to be contributing factors to the healthy siblings' maladjustment.

1. There were no extended family members who offered any support to the parents, patient, or siblings during the crisis of the illness. The paternal relatives who lived in this country withdrew completely, increasing the siblings' feelings of abandonment.
2. One sibling was a fraternal twin of the cancer afflicted child so that the loss of the sick brother through separation and illness disrupted a very special bond which characterizes twin relationships.
3. The mother in Family A viewed the sick child as her "special child" who most resembled her, which made it harder for her to accept his illness, and led her to express overt and covert hostility to the healthy siblings. Parental hostility towards the healthy siblings has been noted in the literature.⁴³

In view of the health care team's extensive interventions in Family A, one can conjecture that the presence of interested professionals, sensitive to the siblings' and parents' needs may have been instrumental in preventing more serious emotional disturbance in this family.

This project was not designed as an experimental study with a matched control group of families whose

healthy children were not involved in the pediatric cancer patient's hospital experience. It is, therefore, not possible to evaluate the effects of Model I with any degree of reliability or validity. The project director's and the health care team's clinical observations suggest that Model I played a helpful role in facilitating the adaptation of healthy siblings in a small number of families.

The parents' and siblings' evaluations described in Chapter VI lend support to this observation.

All three families participated in the study with openness and appreciation. They appreciated the health care team's interest in the healthy siblings. Members of the health care team were extremely responsive to the needs of the siblings once they met them.

The project's findings which include an unanticipated level of parental and professional responsiveness imply that Model I is a viable family-centered treatment approach which should be tested in other childhood cancer centers on a larger scale.

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CHAPTER V
IMPLEMENTATION MODEL II: SIBLING GROUPS

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CHAPTER V

IMPLEMENTATION MODEL II: SIBLING GROUPS

INTRODUCTION

This chapter will describe the implementation of the two sibling groups. Group composition, attendance patterns, and group leader activities will be described to enable the reader to understand the nature and scope of the program. The principles which guided the development of the program will be explicated to facilitate its replication and elucidate its underpinnings.

Model II

The development and operation of two sibling groups constituted Model II. These groups were developed after a review of the health care and group work literature.

OBJECTIVES OF MODEL II

The groups had three objectives:

1. To provide a safe supportive group atmosphere in which siblings could identify and express their feelings of anxiety and isolation.
2. To help siblings overcome their feelings of anxiety and isolation.
3. To explore the feasibility and effectiveness of sibling groups as a method of intervention for providing psychosocial support to siblings.

BACKGROUND

Groups are a frequently employed method of treatment and education of medical patients and their families. Rosenberg and Neil reviewed fifty one articles on groups taken from a spectrum of professional journals. They found that groups in health care have multiple goals which the authors classified into the following categories: information-seeking, patient education, problem solving, psychotherapeutic and prevention.¹ Rosenberg and Neil were critical of the articles they reviewed. They state: "Unfortunately most of the published articles lacked a clear theoretical orientation and such baseline data as the frequency and duration of the sessions; further the rationale for the composition of the group was not given, thus making replication, comparison and evaluation difficult."² The following report of the project's sibling groups incorporates Neil and Rosenberg's recommendations for more systematic and useful group descriptions.

GROUP COMPOSITION

Based on the sibling population available at the Pediatric Oncology Clinic at the time of the study, the investigator developed two sibling support groups. The first group, Group A was offered to elementary school age siblings whose sick sibling was receiving active treatment

at the clinic. The second Group, Group B. was offered to adolescents and young adults whose siblings were also receiving treatment at the clinic. The selection of age as the basis of group composition rested on theories of group work practice. Gitterman's conceptualization of the importance of homogeneity in groups provides one explanation for this choice.

"Composition affects the nature of group development and its direction, i.e. whether the group will move toward mutual aid, disintegration or parasitism. Groups composed of members with common backgrounds (i.e. age, sex, ethnic, social class and common personality capacities and behavior tend to be stable and supportive, quickly developing a group identity. Similar life experiences, concerns, interests and adaptive styles provide members with a sense of commonality and collective stability."³

Only two sibling groups of pediatric cancer patients have been reported in the literature thus far.⁴ Both groups sought to provide cancer related information and support to the siblings. One group composed of 10 siblings aged 9-12 met for five consecutive weeks. The second group met during a special summer program in California. The length, frequency and group composition of that program is not reported. The participants' evaluations were favorable in both groups regarding the information and support they gained from the experience. The emotional interactions between the siblings were not reported in either of the two articles which describe these groups. Consequently, the

investigator could not be certain that the sibling role was a sufficient criterion for group membership if one wished to develop the optimal spirit of commonality and mutual aid in the group.

It was, therefore, hypothesized that the combination of the sibling role and similarity in ages would provide the most favorable conditions for the development of cohesive groups which could accomplish the study's objectives of identifying and alleviating the anxiety and isolation of siblings of cancer patients.

Frequency and Duration of the Groups

Group A met for 8 weeks, Friday afternoons for one and a half hour sessions after school. Group B met for four weeks, one night a week for one and a half hour sessions after work. The number of sessions in Group B. were reduced from the original eight intended because of the heavy work and home commitments of the adolescent siblings who wished to participate in the group. Both groups were led by the investigator and a co-leader.

ATTENDANCE PATTERNS

Group A

A core group of five siblings, three girls and two boys aged 8-12 participated in this group. Four of the five group members attended every session. The fifth group member, the youngest child, aged 8 was only able to attend

three of the eight sessions. His mother could not bring him more frequently and she did not permit him to come with the van which transported the other group members who lived too far to walk or use public transportation. The van was authorized and arranged by the investigator in collaboration with social service administration.

Group B

A core group of five siblings, aged fourteen to nineteen participated in this group. Their attendance was much more sporadic than that of the younger group participants. Four of the group participants attended three of the sessions. One group member attended two of the sessions. None of the members were able to attend all the sessions. They gave practical reasons for non-attendance; lack of transportation, conflict with other commitments, e.g. celebration of parents' anniversary, overtime at work, etc.

The difficulties of securing the commitment of adolescents to group participation have been documented in the literature. The adolescents' age-related ambivalence and fear of acknowledging a need for help have been cited as two main reasons for their resistance to therapeutic groups.⁵

In addition to the regular five group members, two of whom traveled forty miles each way to attend, two siblings joined the group for two sessions only. These

siblings were two brothers, aged 19 and 29 who were already demonstrating serious psychological problems manifested in alcoholism and drug abuse. They did not want to attend regularly because they felt that the group members were too young for them.

The 29 year old sibling had not been recruited for the group since he was considered too old for membership. He asked to join after his 19 year old brother decided to participate. Ironically, while the older sibling was disappointed about the group's composition regarding age, his attendance and subsequent telephone contacts with the investigator helped to bring him to the attention of the professional staff. His desire to participate in the group was primarily an expression of his desire for professional help. This young man was drifting socially and psychologically and he wanted individual counselling to relieve the anxiety and anger he was experiencing as a result of his sister's illness. Her illness disrupted his own life and military career, thrusting him into the role of a caring, supportive father who could not be away from home while his young sister was suffering.

PROGRAM OPERATION

The following sections describe the principles which governed the group program, the roles and activities the leaders performed, and the group process which evolved with the help of these activities.

PROGRAM PRINCIPLES UNDERPINNING BOTH GROUPS

Four key principles derived from group work and group therapy literature guided the group program from its inception:

1. The group support program should help the siblings of cancer patients experience the support and attention of hospital personnel, and recognize that they are not alone with their feelings and fears.
2. The group program should enable the siblings to feel that the group is a safe place in which questions, feelings and thoughts can be expressed without fear of judgement or retaliation.
3. The group program should enable siblings to feel that the group is their group and that they have considerable control over its content and process.
4. The program should enable siblings to feel that they have a right to be concerned with their own needs and that the desire to have fun and to get some pleasure out of life is normal and acceptable.

These principles influenced the group program in all aspects from its location to the way time was used.

Program Location

For Group A, the investigator secured the office of the outpatient clinic's medical director. This spacious attractive office had a large blackboard which the participants could use to draw their feelings when words were inadequate or threatening, or when they became bored with sitting or wanted to show off their artistic skills. The office was near enough to the oncology clinic so the parents felt familiar with the site and felt safe, knowing where their healthy children were when they attended the program. At the same time the office was far enough from the clinic so the children were not constantly reminded that they were on their sick brother or sister's turf. This feeling was expressed by four of the siblings in comments such as: "Bruce would be jealous if he knew that we had such a beautiful meeting room" or "I am glad that we do not have to look at the clinic waiting room all the time. It would make me sad to think of all the injections Monica gets there."

For the adolescent - young adult group a large conference room was used, easily accessible from the main entrance of the hospital, in order to meet the adolescents' needs for independence and control.

Snack food was made available in both groups as a symbol of welcome and giving. In the young sibling group, the snack represented an important intervention and topic of conversation. Several of the group participants were

severely limited in their intake of sweets at home since the children with cancer were not permitted to eat sweets due to the medications they were taking. In order not to tempt or frustrate their sick children, many parents dealt with this restriction by not permitting any sweets into the house, thus depriving all their children of the kinds of "goodies" which were a common part of their lives prior to the sick child's diagnosis and treatment. The snack in the group promoted several exchanges between group members about the themes of change and deprivation in their homes.

PARENTAL INVOLVEMENT IN THE GROUP PROGRAM

In order to reduce parents' potential resistance to the program, they were consulted about every aspect of the program, from the days and hours of the sessions to the selection of the snacks used.

As anticipated in the planning of the program, the parents' completion of the CAAP questionnaire about their healthy siblings prior to the first session served the function of giving parents a sense of control and engaged them in a discussion about their healthy children.

The findings derived from this instrument will be described in Chapter VI.

The parents quickly became enthusiastic supporters of the program. To illustrate:

In Group A, one of the sessions was almost cancelled due to a snowstorm the previous day. The parents were

consulted and they unanimously decided that the group should be held. Three mothers commented: "The kids wait all week long for Friday afternoon, when the group meets. They would be terribly disappointed if you called it off." Let us not disappoint them."

ACTIVITIES OF THE GROUP LEADERS:

The original outline for the group program was intended to identify topics of anticipated interest and provide a basis for the group leader's activities (see Appendix A). Since the program was exploratory, seeking to identify unmet needs, the investigator did not want to use the format described in the sibling literature which relied heavily on educating the siblings about the illness and about the facility in which their sick sibling received his or her care.⁶ Instead, the investigator sought to create a group structure and climate in which the healthy siblings could participate in exploring what they need, and in shaping the program to meet those needs. To accomplish this objective, the participants' ideas and opinions about what they wanted to get out of the experience were solicited in the first group meeting and in subsequent meetings. The group leaders' activities and interventions varied markedly in the two groups based on the members' descriptions of what they wanted to get out of the group experience. This approach to group leadership was based on social group work theory which recommends that group

meetings should reflect the composite expressed purposes of both workers and members.⁷

The leader's activities were guided by the participants' developmental level. For example, latency age children are curious and restless, in need of a variety of activities to sustain interest.

Consequently, their sessions contained a lot more variation from session to session and within sessions. Discussions were followed by physical activity in recognition of their limited attention span.

During the life of each group the leaders assumed all of the worker roles which have been identified in the group work literature. The four major roles include the therapist who is primary helper, the teacher who emphasizes content, the facilitator of mutual helping and the consultant - resource person who helps natural leaders and provides technical assistance.⁸ The roles of facilitator and therapist assumed primary importance in the majority of the sessions.

Group A

For the school age sibling group, the investigator invited other health care professionals when appropriate. One of the pediatric oncologists, an oncology nurse and the oncology social worker attended three out of the eight sessions to give participants the opportunity to ask specific medical questions and meet more of the

professional staff who have come to play such an important role in the sick siblings' lives. In response to their wishes for information about other children's experiences in coping with a sick brother or sister, the participants were given a new book entitled, "When Your Brother or Sister Has Cancer", which they were asked to read at home.⁹ The siblings were told that the book's authors, as stated in the book, were genuinely interested in the siblings' evaluation of the book. The siblings expressed pleasure that their opinions were solicited. All the siblings wished they had received such a book at the onset of their sibling's illness. Individually they wrote letters to the authors of the book to let them know that the book was helpful because it universalized their own experiences.

In response to the young siblings' wishes to have some fun in the group, since there was so little fun in their lives at home, one session was devoted to a collective birthday party, complete with balloons and ice cream. The siblings participated enthusiastically in planning the party which several siblings described as "a chance to be happy, and to feel important."

Enough balloons and trinkets were provided so the siblings could prepare a gift packet for their sick siblings. All the siblings elected to prepare such a packet.

Seven of the eight sessions were devoted to more serious activity and discussion. The sessions included both structured and unstructured time. The group leaders initiated and facilitated the discussion of topics which were designed to offer social support, factual information about the shared life stress of a sibling's illness and an opportunity for emotional interaction with others in the group. Researchers of small groups have indicated that such activities assist group participants in coping with the shared stress.¹⁰

An excerpt from one of the group session in Group A will illustrate both the leaders' activities and, the group's climate:

Johnny (pseudonym) wanted to talk about a fight he had in school today with his best friend. He wasn't sure what started the fight but he decided that he'd make up with his friend because he needed him. The reference to the fight initiated a long discussion about the siblings' perceptions of danger and violence everywhere, at school and at home. Johnny spoke about the tough boys who come to school with knives. Sara described the tough girls in her school who smoke pot in the bathroom. Ron wanted to talk about the dangers at home. He was hit today for pinching his sick sister. He cried and then he was hit for crying. His mother also told him that she had a bad dream about someone dying. Johnny stated that he often thinks that he'll die in a fire. This stimulated an exchange between the siblings about who they would save if there was a fire in their home. Sara emphasized that she would save her pets and everyone else before she saved herself. When the investigator and co-leader questioned this, she insisted that pets are helpless and have feelings too. All the group members agreed that the older siblings should save the younger siblings.

"Sick children should get out first. Possessions should be left behind." When the leaders questioned whether group members felt they had the full burden for saving their younger siblings, only one group member stated that her father assured her not to worry so much. "He'd always be there for her." She felt a great relief in this. None of the other siblings have been given that kind of reassurance by their parents. The co-leaders asked what the siblings did with that feeling of responsibility and burden and what they did to feel protected and safe.

All the participants except Sara said that they go to church. Sara said that she locks herself into her room to feel safe. The co-leaders suggested that the siblings' parents were there for their protection and for sharing the burdens of responsibility with them, even if they can't always tell the siblings this very clearly.

Johnny added that "he can't wait for his parents." For example, he had already figured out what he would do if someone followed him on the street. He would ask a storekeeper to let him call the police. The other group members agreed that this was a good idea and gave additional suggestions to Johnny.

The leaders gave him recognition for figuring out how to solve a problem. The entire group agreed, however, that everyone needs to feel dependent and protected at times. Even grownups need to feel dependent on others.

Discussion

This excerpt illustrates the concrete language the young siblings often used to express the vulnerability and anxiety they were feeling. The unanimous agreement among five young children, 8-12, that they would save themselves last in case of a fire raises questions about their self-esteem and guilt. It also suggests that at ages 8-12, these siblings already perceive themselves as individuals with a lot of responsibilities, for caring for others. The

participants' attempts to master anxiety by developing strategies for escaping from perceived danger reflect their adaptive capacities and their determination to survive even without the protection of their parents. The desire for protection came up in several meetings. One of the siblings commented in two sessions that he wished he could give the investigator's name in school as the person to be contacted in an emergency. He did not feel that his parents would be there for him when he needed them. That feeling was expressed by all five siblings at various times.

LEADER ACTIVITY - GROUP B

Most of the leaders' activities in the older group were verbal only. The leaders' role in this group was that of facilitator and interpreter. The adolescents' greater maturity and attention span permitted the group leaders to use discussion as the primary group activity. The adolescents were developmentally more capable of verbalizing their anxieties directly, in relation to their sibling's illness. They were also more capable of turning to other group members' for support.

An excerpt from a session in Group B will highlight the differences in the two groups.

In the first part of the evening, there was discussion about the fact that perhaps peers and adults stay away from the siblings and their family members

because they do not know what to say when cancer strikes a child in the family. In the second half of the meeting, Ellen wanted to return to this topic because it struck a responsive chord in her.

She related emotionally that she finds herself not knowing what to say to the mother of a 10 year old clinic patient, Barbara, who was in remission but suffered a relapse last year and died. Ellen's and the late child's families had known each other from the clinic and socialized a lot. Ellen's sick brother and the dead child were good friends. Ellen related that she cannot get the dead child out of her mind. The child, a very bright good humored articulate patient died of sepsis, bacterial infection which spreads through the body but Ellen stated that in her mind, Barbara died because she just gave up. Before she died, the 10 year old patient verbalized that she did not want to go through all the treatments again and to have the surgery which might save her life. Ellen admired the child and often wonders whether the dead child's mother resents her brother for living. She also worries about the guilt her brother might feel for surviving his friend. Ellen described with a lot of pain how uncomfortable she feels when the deceased child's mother comes to their swimming pool with another daughter, but without Barbara. Ellen still feels the void and does not know what to say to Barbara's mother.

The group members were visibly shaken by this story and conveyed a lot of empathy for Ellen's pain. They also asked anxious questions about relapses and the chances of preventing them.

At the end of the group, Ellen stated that she was surprised by her own behavior tonight. She had never talked about this before. Initially she was just numbed, and couldn't even cry at the funeral. Until now, whenever Barbara's mother called or came to the house she tried desperately not to stay alone with her because she would not know what to say.

The co-leaders assured Ellen that using the group for the expression of such heavy feelings was perfectly appropriate. The leaders also suggested that Ellen hold on to the good memories of having known Barbara, rather than only to the memory of her death.

Discussion

This excerpt illustrates some of the isolation and anxiety the older siblings experienced as a result of their sick sibling's illness which thrust them into situations with which they did not know how to cope. Ellen's inability to voice her anxiety and conflicted feelings to anyone until this group meeting suggests that the group provided a unique forum for the expression of these feelings. The group also made it possible for Ellen to begin an appropriate process of mourning for her late friend, a process which was long overdue, and was essential for preparing Ellen for eventual adaptation to her own sibling's possible death.

SUMMARY OF GROUP PROCESS

The group leaders assumed the responsibility for establishing a climate of interest, acceptance and trust in the group from the first session. The purpose of the group was explained to reflect the hospital staff's desire to get to know the siblings of patients, based on the realization that staff members know the patients and parents but rarely have the chance to meet the siblings and find out what some of their concerns and worries are regarding their sibling's illness. It was also assumed that siblings would have something in common, since having a sick child in the family is very tough on everyone and leads to many changes in most families of cancer patients.

This introduction enabled the participants to share their concerns and ideas with each other as well as with the group leaders. In the early sessions in both groups, the participants demonstrated their hunger for attention and appeared to relish the opportunity to talk about themselves, their experiences at home, at school, and with their friends. They seemed surprised that someone in the hospital was genuinely interested in them.

They related to each other on an intimate, friendly level and showed empathic concern for each other. For example, in the older group, when two of the members described their sister as both retarded and leukemic, the other group members' quickly conveyed their empathy and admiration for these siblings' ability to handle such a dual burden.

In the younger group, the rapport was also quickly established. The children were not only hungry for attention, they were also hungry for company and enjoyed the opportunity to be with other children "who knew what they were talking about."

As the groups progressed, participants' in both groups were increasingly willing to identify and express their feelings of anxiety and isolation and to solicit the group's help in alleviating them. For example, in the sixth session of the young group, one 9 year old member brought along her huge doll whom she introduced as her best friend. She explained that she needed this sister because she often feels like an only child.

"T. has leukemia and R. is autistic, so I need someone on my side." The group responded to her plight and immediately began to make plans about how they will stay in touch with each other after the group ends. Addresses were exchanged and much mutual affection and interest was expressed. Because the young group had become such a cohesive, caring group whose members filled a void in each other's lives, the void of isolation and loneliness, they found termination very difficult. For several weeks before termination they had pleaded for additional sessions or longer sessions to ward off separation.

In the older group, although participants did not make the same commitment to membership and participation that characterized the younger group, the participants at each session appeared to trust each other and felt increasingly free to share fears and doubts and to alternate intellectual discussions with more affective, personal revelations. The older group whose attendance pattern prohibited the development of a close knit group, nevertheless found termination a matter of regret. Four of the siblings wanted to continue the group at least on a monthly basis. "We have a lot in common, and we can learn from each other", was a frequent comment.

Discussion

Several group work therapist have concerned themselves with stages of group development. Garland

Kolodny and Jones have constructed models for stages of group development. Bennis, Thelen, and Schutz have also been identified with this theoretical orientation. Five general phases of group development, preaffiliation, power and control, intimacy, differentiation and separation have been conceptualized by most of these authors as the stages which occur and recur throughout group life. The most striking phenomenon about the two sibling groups was the speed with which the stage of intimacy was reached, and the relative absence of power and control issues in both groups. The investigator assumes that there were at least two reasons which explain this phenomenon:

1. The siblings were yearning for an opportunity to express their feelings about the sick children's illness. Their desire for ventilation and acceptance outweighed their fear of risk and exposure.
2. The commonality of having a sick sibling represents a powerful bond which enabled the siblings to relate to each other easily and to feel understood, and safe.

THE EFFECTS OF MODEL II: SIBLING GROUPS

The evaluation of this Model is described in Chapter VII. The following brief summary merely highlights the key observations recorded during the implementation of Model II.

The excerpts from the group illustrated that the use of the group modality provided siblings with an opportunity to experience a mutual aid system in which they shared common concerns and ideas for handling them. Gitterman points out that "by its very nature, the group mutual aid system universalizes individual problems, reduces isolation and mitigates stigma."¹¹ The siblings in both groups related to each other on an intimate, caring level. They listened to each other with empathy and interest. They rarely interrupted each other and often expressed warm concern for each other. In Group A, for example, it was striking that during the snack period, if only one or two cookies were left, the siblings turned to each other to see who wanted it. No one ever grabbed food or monopolized time in the group. In view of the siblings' ages 8-12, and feelings of personal deprivation, this was an unexpected act of unselfishness and consideration.

It is possible that children who have a sick sibling mature faster and learn to be more considerate than their normal cohorts who do not have to face the challenge of a sick sibling whose needs tend to take priority in all areas of the siblings' lives.

NOTES CHAPTER V

IMPLEMENTATION OF MODEL II: SIBLING GROUPS

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3. Alex Gitterman, "The Use of Groups In Health Settings", in Rosenberg, Lurie, Pinsky, op. cit. p. 14.

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5. Irving Berkowitz, Editor, Adolescents Grow In Groups, Brunner, Mazel, New York, 1972.

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10. Mark D. Schwartz, "Situation Transition Groups: A Conceptualization and Review", American Journal of Orthopsychiatry, Vol. 45, No. 5, pp. 744-55, October 1975.

11. Gitterman, op. cit., p. 7.

CHAPTER VI
FINDINGS: MODEL II

CHAPTER OUTLINE

- A. INTRODUCTION
- B. SOURCE OF DATA
- C. DATA ANALYSIS
- D. FINDINGS GROUP A
- E. GROUP B
- F. DISCUSSION
- G. ANALYSIS OF THE CAAP INSTRUMENTS
- H. SUMMARY OF FINDINGS: MAJOR SOURCES OF SIBLING ANXIETY AND ISOLATION IDENTIFIED IN BOTH MODELS OF THE STUDY

CHAPTER VIFINDINGS MODEL II: GROUP TREATMENTINTRODUCTION

This chapter will describe the findings of the two sibling groups implemented in the project. The groups are reported separately since the concerns and developmental tasks of different age groups have important implications for age appropriate practice.

SOURCE OF DATA

The findings in this chapter are derived from the tapes and process recordings of the group sessions. The young sibling group was tape recorded and the tapes were transcribed verbatim. Taping was suspended in the older group after the first session, at the participants' request. Process recordings of both groups, based on copious notes were entered in a log immediately after each session ended. The process recordings, written by the investigator, captured both verbal and nonverbal communications.

This method of recording is recommended by Epstein and Tripodi to preserve the greatest possible authenticity of process recording.¹ To increase the reliability of the recording, the investigator and co-leader reviewed each recording jointly, to check for error or bias. The CAAP instruments completed by the parents of the sibling group

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participants constituted an additional source of data for the findings.

DATA ANALYSIS

The technique of qualitative content analysis was applied to each process recording to identify thematic content areas relevant to the purpose of the study.

Content analysis is a research procedure for obtaining systematic, quantitative and qualitative information from written documents, films, tape recordings, photographs, etc.²

Each session was identified as a unit of analysis. The categories for analysis and their behavioral referents were developed after a preliminary study of the documents to be analyzed. This was consistent with accepted methods of content analysis.³ The investigator developed a simple scale for coding the frequency of statements and behaviors which reflected the anxiety and isolation of the groups' participants, in relationship to their sibling's illness.

Statements which were expressed by several group members, and those which surfaced at several sessions were grouped into themes. In order to increase the reliability and validity of the coding, a graduate social work student was employed as a research assistant to act as a second rater and coder.

The findings below represent the key themes which emerged in the two groups. Only the themes which relate to the project's focus on sibling anxiety and isolation will be reported and analyzed. Quotations from the participants will be used to highlight the intensity and complexity of the siblings' experience.

The Findings

Previous research and clinical practice with siblings of pediatric cancer patients has indicated that siblings suffer from anxiety and isolation. These feelings were assumed to be related to parental preoccupation with the sick child.⁴ Spinnetta, Kramer, Sourkes and Kaplan reported that parental preoccupation with the needs of the cancer patient leads to feelings of abandonment and loss of self-esteem in the siblings.⁵ Concerns over the visibility of the illness and concerns about contagion and vulnerability to illness have also been identified by several authors. Anger towards the parents and towards the sick child has been reported in relatively few articles.⁶

The present study confirmed that the special attention lavished on the sick child by the parents represents a major source of anxiety and anger for latency age siblings. Feelings of vulnerability and fear of illness were also found to be prevalent in the school children and adolescents who participated in the groups. Concerns over the visibility of the illness did not emerge as an important issue in the present study. Fear of the

sick sibling's death, however, was found to be a powerful theme in the lives of both groups of siblings.

Group A - The Elementary School Age Group (Ages 8-13)

The predominant themes in the young sibling group were 1) feelings of deprivation, displacement and injustice, 2) feelings of anger, 3) loneliness and 4) feelings of vulnerability. Each of these themes will be explicated below.

Theme I. Feelings of Deprivation, Displacement and

Injustice

The siblings in the group perceived their parents as overindulgent of the sick child and consistently unfair to them. "All my problems began when T. developed leukemia. My parents stopped understanding me. They worry about T. all the time and they let him get away with murder." stated one sibling ruefully, amidst groans of agreement and identification from other group members. This perception has been widely reported in the literature.⁷ The participants considered the parents' differential attitudes towards fighting between siblings as the most blatant example of the parents' unfairness. The sick children were often permitted to hit their healthy siblings who were never permitted to hit back. Children with leukemia and other blood cancers bruise easily and are always perceived by their parents as frail, in need of extra protection.

One nine year old girl in the group described being frequently angry at her four year old leukemic brother who "was a pest, interfering with her homework and possessions." Like all the other siblings in the group, she was not permitted to hit or "touch" her sick brother. She vividly related how in a moment of acute fury she chased her little brother around the apartment. Her mother picked up the sick child, to protect him and shouted: "Don't you hit my child!" The sibling described her feelings during this episode, as well as during many others in her life: "My parents act as if I wasn't also their child." The other siblings identified easily with this girl's experience and recounted their own experiences in always losing out to the favored child. Four of the five group members harbored intense feelings of wanting to run away. Two children kept a suitcase packed at all times. One sibling who was later referred for individual and family therapy indicated on three occasions that he often wished he was dead.

The siblings' feelings of deprivation and displacement reflected their own unmet needs for continued parental support, protection and attention which was consistent with their stage of psychosocial development. These siblings were in a developmental period which Freud considered latency, and Ericson considered the period of industry. In order to master the skills and challenges of school work, the primary developmental tasks of this

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period, the siblings needed reinforcement of their sense of competence and worth from their parents.⁸ Instead, they were living in an environment which generated feelings of inferiority since the parents consistently treated the sick siblings' needs and feelings as more important than those of the healthy siblings. Newman writes, "The social environment also generates feelings of inferiority through the process of social comparison. Particularly in the school setting but even in the home, children are confronted with statements suggesting that they are not as good as some peer, sibling or cultural subgroup."⁹ The siblings who participated in the group consistently felt that they were not as important or valuable as their sick siblings. In personal interviews, their parents confirmed that they were treating the sick child and his sibling very differently, recognizing that this often made their healthy children feel jealous and unloved.

Developmentally, the siblings lacked the cognitive and affective capacity to understand that their parents' behavior was based on the sick child's medical needs, rather than a lack of love or appreciation for them.

On some level, the siblings understood the pressures and dilemmas their parents faced. As one sibling poignantly summarized for the group: "The worst thing about all the anger you feel inside, is that there is no one to blame." Their appreciation of the parents' burdens and worries left the siblings even more confused and

anxious, unable to assign blame, a technique used by children and adults as a defense against anxiety, guilt and anger.

The siblings preoccupation with deprivation, anger and loss of attention led to a lot of confusion and anxiety. "Even if you feel bad for your sick brother or sister, you still want your parents too," stated a wistful 12 year old girl. Eight year old T. responded, "It's all so confusing; you are mixed up by so many things." Confusion, ambivalence and resultant anxiety emerged as important issues in several sessions. In an extremely moving session, several siblings described the pain of having to give up a beloved bird or dog after the sick child began treatment. Pets carry many germs and therefore pose a serious threat to the infection-prone child whose immunity is suppressed when he receives chemotherapy. Two of the parents did not give any explanation to the healthy siblings about the reasons for putting a pet to sleep or giving him away. The lack of explanation left the siblings feeling devastated and angry.

Theme II - Feelings of Anger

The children were frightened by their feelings of anger. Developmentally, they were limited in the range of options available to them for expressing or mastering these negative feelings.¹⁰ Two of the male siblings acted out their anger through increased fighting in school. One girl

punched the wall in her bedroom so consistently that she made a hole in it. She was afraid of her parents' reaction and blamed the damage on her autistic brother. This further increased her anxiety and guilt.

When asked whether they were able to share these feelings with their parents, several siblings reported attempts at conveying their anger about unjust treatment to their parents. The parents' responses were not supportive, leading the siblings to fear that if they continued to express their anger, they would get hurt or be even more deprived.

This fear of expressing negative feelings was first articulated by Cairns et al. who studied the adaptation of healthy school aged siblings in 71 families of school aged pediatric cancer patients. In analyzing the results of the Thematic Apperception Test and two other projective tests administered both to the patients and their siblings, Cairns et al. found that the siblings were much less likely than the patients to express negative feelings towards other family members, particularly their mother and father. The authors noted that "It was safer for them to assign these negative feelings to 'nobody' on the Family Relations Test."¹¹ The authors surmised that "This reluctance to express anger probably reflects insecurity about their precarious position in the family, a fear that anything they say or do may make things even worse."¹² The present study lends support to Cairns et al's speculations.

Theme III - Loneliness

Since the parents could not be approached safely with feelings of anxiety, frustration and loneliness, the siblings in this group had made periodic vain attempts to share the feelings with friends in order to reduce the sense of isolation and anxiety they experienced. Unfortunately, friends were either uninterested or developmentally incapable of responding in ways that were helpful.

One nine year old girl who wrote and read an essay for her English class about having a sibling sick with cancer found that only the teacher was interested enough to ask questions and express sympathy. To make matters worse, the sibling found herself teased in the lunchroom as "Miss Goodie Goodie." These unsuccessful attempts to connect to peers on a meaningful level left the siblings feeling even more alone with their problems and fears. One nine year old boy considered a two year old child in the building his best friend. This toddler was always happy to see him, and made him feel important and wanted. The siblings' loneliness was compounded by a lack of social interaction outside of school. None of the siblings in the group participated in afterschool programs. The two girls in the group were allowed to visit friends periodically in their friends' homes. Two of the boys were active in their

church and sang in the church choir. That was their only social outlet. All the siblings indicated that they used to have more family outings and social experiences prior to their sibling's illness. Their parents' financial and emotional resources became more limited after the diagnosis so that social and recreational activities for all family members were given a low priority. This finding was also observed in the family-centered approach of the project, and has been reported in the literature.¹³ Thus, Sourkes stresses the value of social and recreational opportunities to provide siblings with opportunities for mastery and support, and for distance from the illness experience.¹⁴

The Siblings' Experience in Connecting to Each Other:

Several authors have questioned latency age children's abilities to offer support to each other, given their level of cognitive and moral development. Piaget suggests that prior to the adolescent stage of development children are not capable of altruistic behavior or genuine empathy.¹⁵ In the sibling group, the participants, aged 8-12 displayed a very mature capability to identify with group members and to be both verbally and non-verbally supportive. Their sensitivity and maturity in this area may reflect their experience of having to grow and mature at a faster rate than their normal counterparts who are not confronted with the challenge of a fatally ill sibling in the family.

Theme IV - Vulnerability

The theme of vulnerability which emerged in several sessions had two components, vulnerability of the sick child, and the siblings' own vulnerability to illness and contagion.

Group members recognized their sick siblings' great frailty. Frequent unsolicited comments such as "You never know about leukemia" suggested that the siblings were aware of the possibility of their brother or sister's death. One girl who had already lived through a clinic patient's death described with great sadness how she and her autistic brother cried separately upon sensing their leukemic brother's grief about his friend's death. "Just imagine, even my autistic brother cried, and he is not supposed to feel things like a normal person," related this articulate sibling who was mature beyond her years.

A sense of danger, damage, and possible death was ever present in the well siblings' lives. They perceived danger, not incorrectly, even in the treatment their sick sibling was receiving. In the session attended by the pediatric oncologist, the siblings expressed their great anxiety about radiation therapy. Four of the siblings had heard their parents argue about the pros and cons of this form of therapy, in view of its serious long term side effects and risks. From school and the media, the siblings have already learned that radiation may be very harmful,

and is something to be afraid of, as in nuclear radiation, or too many x-rays. Consequently, the siblings worried whether the radiation treatments may harm rather than help their sick siblings.

Vulnerability in terms of the siblings' own potential for becoming sick themselves was addressed directly in at least two of the meetings. When asked whether the siblings ever wondered about getting leukemia themselves, the answer was a resounding yes, with two children adding: "I often think it may not be so bad. Then at least you would get all the presents and would not be blamed for everything."

In the session attended by the pediatric oncologist most of the questions related to the causes of cancer. "What causes leukemia and why do some of the children in the family get it and others do not?" was a typical question.

When the physician asked whether the siblings wondered if they or their children might become ill too, the siblings initially denied it, the boys adding self-consciously that they were not thinking about having children yet. The girls acknowledged that they did think about having children and worried whether their children might have cancer as well. This finding regarding feelings of vulnerability is consistent with Sourkes' analysis of her psychotherapeutic work with siblings.

In her insightful description of themes which have emerged in her clinical work with pediatric cancer patients and their siblings, Sourkes noted that identification with the patient's illness is common among siblings. She writes:

"The fear of taking ill with cancer runs high among a sibling group. There is ample reason for this frightening identification. The siblings see many similarities between themselves and the patient. In the same family, past experiences that affected one child often affected another. Thus, it is only a matter of extension that an illness which could befall one child could just as easily befall another. This logic is especially true when siblings cannot stipulate either cognitively or emotionally a cause for the illness. The apparent randomness of events leads the sibling to think: Why not me too?"¹⁶

In the sibling group, the visiting oncologist gave an honest essentially reassuring report about the causes of leukemia, emphasizing that only 1 in 20,000 children develop cancer and that only certain children, e.g. those with Down's Syndrome are known to have a high probability of developing cancer.

In their evaluation of the group program, described in detail in Chapter VI, the siblings rated the discussion about the causes of cancer as one of the most valuable aspects of the program. Three participants recommended more extensive discussion in future programs about why some children in the family develop cancer and others do not. This recommendation suggests that the siblings' anxiety regarding their own potential for contracting cancer was

not totally alleviated in the group. It also suggests the possibility that some siblings harbored still unresolved feelings of guilt about their sibling's cancer at the conclusion of the program. It is also conceivable that for siblings in this age group (8-12), cognitive mastery through the acquisition of important information and knowledge is the most helpful age-appropriate mechanism for coping with anxiety.

DISCUSSION GROUP A - AGES 8 - 13

The concerns expressed by siblings in the latency group have serious implications. The pervasive feelings of being less important than the sick child led to lowered feelings of self-esteem and strong feelings of anger which the children found overwhelming and frightening. According to psychoanalytic theory, loss of self-esteem and internalized feelings of hostility are two of the major antecedents of childhood and adult depression.¹⁷

One of the participants, a nine year old boy was already displaying several signs of clinical depression. These included difficulties in sleeping, inability to concentrate, somatic preoccupations, poor school performance and flat affect. This child was referred for individual and family therapy as a result of the group. The other siblings in the group appeared to be coping with their anxieties and losses relatively well. However, their dependency needs were not adequately met at home and their

opportunities for social interaction were severely constricted. The academic performance of three of the five children in the group went down markedly after the onset of their sibling's illness. This finding was consistent with the predictions of Cadarang regarding the intrusive effect of a child's chronic illness on his siblings cognitive performance. Cadarang studied 36 children (ages 6 1/2 to 15) who had diabetic siblings matched with a control group of 36 peers who had healthy siblings. She compared the cognitive levels of the two groups and found that the siblings of the diabetic children conceptualized illness less accurately than did the control group of children with healthy siblings. She attributed her findings to the decalage phenomenon described by Piaget in which stress acts as an intrusion factor to produce lower levels of general cognitive function. Cadarang concluded that the long term stress related to the effects of a sibling's diabetes may interfere with a sibling's cognitive and academic performance in an ongoing manner.¹⁸

Brown and Sunshine who offered group services to latency age children of alcoholic parents offer another compelling reason why the findings of Group A must be taken seriously: "One of the primary tasks of latency is learning which leads to mastery over the environment and increased self-esteem. Learning and related school activities, for example, sports and social clubs facilitate the neutralization of aggression and the sublimation of the

instinctual drives. In order for optimum learning to take place, a child needs a consistent environment that is adequate in affective nurturance and parental approval."¹⁹ The siblings in the group described family situations in which support and gratification of esteem needs were often inadequate due to the stress and demands of the cancer patient's illness.

The pediatric cancer patients' interests also demand that the siblings' concerns be carefully evaluated.

The siblings' reports about the parents' overprotectiveness of the sick child, and their interference in the siblings' interactions raise important questions about the potential harm this type of parental overprotection may inflict on the sick child's personal development. Minuchin, in discussing families of children with an anorectic child, strikes a relevant note:

The parents in an anorectic family typically intervene in arguments between the children, often to protect the anorectic child. Such intervention allies the anorectic inappropriately with her parents and robs her of the opportunity to participate in peer negotiations as an equal. The therapist must create a buffer zone delineating the sibling subsystem. He may talk with the anorectic about the necessity of learning to fend for herself among her siblings. If the sibling subsystem operates in a protective fashion, he can assure the siblings that they do not have to worry so much about the anorectic. The child needs opportunities to learn how to accommodate to positions in which she has less power and to act autonomously in situations of more power. Human social systems and life itself are organized hierarchically. It makes sense for the child to learn how to negotiate

and accommodate himself in hierarchical situations in the family.²⁰

This analysis of the child's need to learn to accommodate to various positions of power is highly applicable to the pediatric cancer patient who, as a cancer survivor may not always be in a position to control his family and environment with the power of his illness.

GROUP B: THE ADOLESCENT SIBLING GROUP - AGES 14 - 19

The literature to date reveals relatively little exploration of adolescents' experience with cancer-afflicted siblings. Adolescent siblings have been included in the samples of a few studies but only Cairns and Spinnetta have analyzed their findings according to age groups.

Cairns found that in her study of cancer patients and their siblings from 71 families, the adolescent siblings exhibited considerable anxiety about school failure. This finding was not supported in the present study. Spinnetta et al. found that adolescent siblings perceived their family as significantly greater in conflict and lower in cohesion than did the pediatric cancer patients themselves. No such comparison was attempted in the present study.

A recent article by Mufson was found to have great relevance for this study. Examining the impact of sibling death during adolescence, she presents three in-depth case

studies of adolescents from upper middle class families who were 13-16 years old when their siblings died. Two of the deaths occurred ten years previously, one only two years ago. Two of the siblings died from cancer. After a perceptive application of Bloss' psychoanalytic concepts to her study, Mufson points out that the death of a sibling had a very destructive impact on the subjects' ability to pass through the separation-individuation process of adolescence.²² She found that the siblings in her study were overwhelmed by feelings of grief and rage but were unable to mourn openly.

Their inability to mourn resulted in their emotional isolation from family and peers. Mufson cites the adolescents' desire "to act like everyone else," and their fear of regression, engulfment, and resultant dependency as the main reasons for the adolescents' inability to mourn. She observed that in her case studies, the complex problems of coping with sibling death during adolescence led to long term difficulties such as overidealization of parents and pseudo-separation rather than true psychic separation from them. She notes:

"Although they were married adults living in different cities from their parents, two of the siblings still looked to their parents for narcissistic supplies, still tried to please their parents and exhibited a striking lack of differentiation from them."²³

Mufson recognizes the limitations of her small homogeneous sample and calls for further investigation of the effects of sibling death during adolescence.

The present study focused on adolescents whose siblings were still alive, and were receiving active treatment. The experience with the adolescent sibling group suggests that sibling illness as well as sibling death impacts in many ways on the adolescent's ability to spend his or her energies on the developmental tasks of adolescence, and to individuate and separate from family members without enormous anxiety and guilt. This observation will be elaborated, in the sections that follow.

Themes of the Adolescent Sibling Group:

Overview

The adolescent siblings were not as angry at their parents as the siblings in the younger group. This probably reflected their greater maturity and independence which reduced their need for parental attention.

Theme I: Fear of Death and Feelings of Vulnerability

The adolescents' fear of death and feelings of danger were as pronounced as those in the younger group, although they were expressed differently. For example, the adolescents worried considerably more about the risk of complications and failure to respond to the treatment. The participants whose sick brother or sister had already

pulled through some critical incidents worried when the time might come when their sibling would not pull through. Those who lived at a considerable distance from the hospital wondered whether they'd always get to the hospital in time in an emergency. When asked if they ever worried about getting leukemia themselves, the siblings indicated that they were much less concerned about that, than about the possibility of catching an infectious disease which might prove fatal to their sick sibling. They worked hard at staying healthy, knowing that a common cold for them, might mean pneumonia for their immuno suppressed brother or sister.

They also expressed considerable anxiety about the impact of the illness on their parents. Four of the siblings vividly described the changes they perceived in their parents. One or both of their parents became workaholics after their sibling became ill. Although the siblings recognized this as a coping device, they feared the toll overwork extracted from their parents. Since they experienced their entire families as more vulnerable, the possibility of their parents' illness was not far from their consciousness. One 15 year old boy volunteered that "I used to think I could get along without my parents. I often thought I could run away and manage. Now I don't think I could." When asked if these thoughts were prompted by concern that something might happen to his parents, too, the sibling freely acknowledged that he worried about that

a lot. Another sibling described her mother as the glue which kept her family together. She thought her family would fall apart if anything happened to her mother. The changes they perceived in their parents, such as loss of zest for life, overwork and changes in values and priorities saddened the siblings whose developmental struggle for separation and independence was clearly affected by their overwhelming sympathy for their parents and sick siblings.

In one of the group sessions which addressed their anxiety about their parents' well being, the siblings suggested that the group leaders run a group for their parents, similar in style and purpose to the sibling group. "You'd take some of the pressure off us that way. By helping them, you'd indirectly also be helping us."

The participants' concerns about their parents' physical and mental health reflects both their love of their parents as well as their fear that they would lose their parents and would not be able to cope with the loss. Wolfenstein compares the stages of adolescence to mourning and states that in adolescence, there is a protracted and painful decathexis of those who have until now been the major love objects - the parents....

Remembrance, nostalgia for the past and reminiscence characterize both adolescence and mourning. In Wolfenstein's view, until a person had undergone the trial mourning of adolescence, she is unable to mourn.²⁴ For

the adolescents in the sibling group, mourning was going on at several levels. They were mourning the parents as they used to be, they were mourning their sick sibling's illness and a way of life that was dramatically altered by the illness. The siblings ability to decathect from their parents and to engage in age-appropriate adolescent activities was complicated by this pervasive mourning process. Their ability to decathect from their parents was also affected by their feelings of obligation towards their parents whose pain and emotional burden they understood with great clarity. A remarkably perceptive 16 year old who was mature beyond her years summed up the dilemma graphically. When asked what group members considered the most difficult aspect of having a sick sibling, this youngster responded, "Having to care so much and being burdened by the responsibility of caring."

As an illustration, she described the experience of being home night after night when her leukemic sister had high fevers and was vomiting a lot due to treatment complications. The healthy sibling stayed home to help her mother to clean up, and to bring the patient's fever down. She wondered if she was selfish for resenting this role sometimes. To defend herself against guilt, she rationalized that she resented the role because she hated to see her sister suffer.

Theme IIFeelings of Burden for the Sibling'sPhysical and Mental Health

All the participants in the group felt quite burdened by their strong sense of responsibility for their sick sibling's physical health and emotional well being. One fifteen year old described wistfully how his life had changed when his 13 year old brother developed leukemia and found himself abandoned by his friends at school and at home. The healthy sibling began to include him in all his social activities, even though tagging his kid brother along, or staying home when the patient felt sick imposed severe limits on the sibling's social life. Another seventeen year old girl spoke sensitively about her fear that her brother's seemingly perfect adjustment to his illness may just be a cover for his true feelings. She noticed that he adamantly refused to name his disease to others. No one could mention the word leukemia, not even during a healing mass celebrated in church in his name. She also noticed that her sick brother was always eager to prove himself and took many chances to demonstrate that he was as good as everybody else. She wondered whether as a good sister, she should find ways to help him talk about how he really feels. A 29 year old sibling who was present in this session stated emphatically that he saw this task as her responsibility. He felt that the healthy siblings had to be there for their sick siblings at all times. The

sick children "put up a good front but in fact they have great trouble managing their disease and their fears." This young adult had to leave the army twice, to come home to help with his sister's care.

Theme III - Conflict About Pursuing Their Own

Needs and Lives

In addition to feeling anxious about their responsibility for their sick sibling's physical and mental health, the older siblings also experienced considerable conflict about their desire to get on with their own lives, yet be present when needed. One 16 year old girl was away in Sweden when her sister was hospitalized with treatment complications. The guilt and anxiety imposed by her absence from home, coupled with the resentment over not being able to enjoy a long planned well deserved trip, led to many conflicted and confused feelings.

A nineteen year old brother in a fatherless home assumed the parental role in the initial stages of his sister's illness. He accompanied her to the clinic for every treatment and was her main source of support. He withdrew somewhat after he failed high school and found himself overwhelmed by too much responsibility. He felt guilty about his withdrawal and talked ruefully about the fact that his sister would probably want him to continue the intense, supportive role. He sought the group's permission to get on with his life, to get a job and finish

his high school equivalency. Even after this support was granted, his anxiety and guilt remained high.

Theme IV - Conflicted, Ambivalent Feelings About the
Relationship with the Sick Child

This emerged as another theme, with heavy overtones of anxiety and isolation.

One girl described with great sensitivity, and much affect, two years after the event, how she and her healthy brother used to stay up late nights when their sick brother was first hospitalized, wondering how they would relate to the patient when he came home. As the middle child, the patient was "the odd man out in the family." "Would we still be able to tease him and fight with him, or would we be so filled with pity that we would not know what to say to him?" The struggle of caring for the sick sibling, without overprotecting him was a struggle every group participant was engaged in. "I let Lisa walk all over me when she first got sick. I gave her whatever she wanted and she became a monster, always demanding something, until I found myself resenting her. Now that she is in remission, I can treat her more normally and we have a good relationship."

The adolescents whose parents sent the sick child to school and tried to normalize relationships and behavior in the family, were the most comfortable in finding the right mix of caring without overprotecting in their relationship

with the sick sibling. However, even for these siblings, the relationship was tainted with anxiety and uncertainty.

A 16 year old sibling's reaction to her brother's smoking illustrates this observation poignantly. Upon finding her leukemic kid brother smoking, the sibling felt that she should report this to her mother. "Ted already has one form of cancer. He cannot be allowed to risk lung cancer as well." On the other hand, there was longstanding understanding among the siblings in this family that "siblings do not rat on each other." Consequently, this caring sister could not deal with her brother's smoking without feeling guilty one way or another.

Theme V - The Need to Control or Withhold

Information About the Illness

Uncertainty about people's responses to a brother or sister's cancer was a major source of anxiety and isolation for the adolescents. One sibling, an A+ student whose school work suffered during her retarded sister's initial hospitalization for leukemia, decided to take the risk of confiding in her teacher about her sister's illness. The teacher's response, "damn, it isn't fair" was exactly as needed. It was sincere, empathetic and free from pity. This sibling and her sister found that after a while their sister's leukemia was not a topic of sensation or gossip. In fact peers and adults began to treat the sick sibling more like a human being after the diagnosis. "They treated

her like a freak when she was just retarded."

All the siblings were very selective in how and when to share information about their sibling's illness. The reasons for not sharing information with friends or teachers ranged from fear of pity to the more prevalent fear of gossip. Uncertainty about how people would react to the news made the siblings very hesitant to share information freely. "I told one girl, whose father had died. I figured, she'd understand."

Voysey, who studied the parents of disabled children found that the families of disabled children are engaged in "impression management", controlling information about the illness, deciding who to tell what. Voysey points out that "letting others in may have definite advantages in terms of emotional support and practical help, but the advantages must be weighed against the cost of involvement. Too little help may be preferable to, too much sympathy."²⁵ The youngest member in the group described how upset she was when she overheard two students whispering behind her back, "she is that girl's sister."

The group participants' experiences with their peers' reactions to the illness varied. Some were extremely responsive, others were disinterested. The siblings appreciated the peers who were supportive and were angry at those who did not convey "the right response." "I told one girl who I thought was my friend that Lisa had leukemia. She did not call me for two days and when she

did, she didn't even ask about Lisa. What kind of a friend is this? I had to admit to myself after a while that she wasn't a true friend." Hypersensitivity during the early period of diagnosis was very common. The sibling's preoccupation with the illness, and their additional responsibilities at home affected some of their social relationships in an ongoing manner. "How do you go out at night when your sister is home throwing up? I am not saying this because I feel sorry for myself. It's just a fact of life, and you learn to accept it. You keep yourself so busy, that you don't have time to think about how unfair this whole illness is."

Keeping busy was a coping device for several of the siblings. After school jobs represented a legitimate way to earn some extra money and gain some distance from the illness. However, anxiety was not left behind. Four of the five siblings indicated that they called home several times a day to "check up on things, and make sure that nothing was wrong."

DISCUSSION GROUP B - AGES 14 - 19

On the whole, most of the siblings were coping relatively well with the illness experience. However, their overwhelming concerns for their parents and sick siblings interfered with their ability to devote their energies to the developmental tasks of individuation and separation. The picture that emerges from the adolescents'

descriptions of their family lives after the sick child's diagnosis is reminiscent of Ericson's description of families adjusting to the presence of a baby.

"It must be added that the smallest baby's weakness gives him power. Out of his very dependence and weakness, he makes signs to which his environment (if guided well by a responsiveness based on both on instinctual and traditional patterns) is peculiarly sensitive. A baby's presence exerts a persistent and consistent domination over the inner and outer lives of every member of a household. Because these members must reorient themselves to accomodate his presence, they must also grow as individuals and as a group."²⁶

In the households of the adolescent siblings, the sick children's presence exerted a domination over the inner and outer lives of the family members that was even more powerful than the domination of a baby since fear of death was always present. Some of the siblings in the group appeared to have grown as a result of the experience, others were heading for serious problems in separating from their families and getting on with their lives and with the age-appropriate separation and individuation process. This observation suggests that professionals who work with pediatric cancer patients who have adolescent siblings must be especially sensitive to the potential impact of the illness upon the adolescent's maturation and development. For some families, professional intervention may be indicated to enable the adolescent sibling to proceed with

his normal growth and development. The parents in these families often welcome the healthy adolescent's physical presence and support, in the home. They have little emotional energy to engage in the normal conflicts with adolescent children and cannot be expected to facilitate their healthy adolescents' separation from home during the illness, when most of their own energies are devoted to coping with their anxieties and the realities of the sick child's illness and treatment.

ANALYSIS OF THE CHILD AND ADOLESCENT PROFILES,
COMPLETED BY THE PARENTS OF BOTH GROUPS OF SIBLINGS

The CAAP instrument was not found to be as useful for this study as it was anticipated. The instrument was not sufficiently discriminating to yield adequate data about sibling anxiety and isolation. Some of the items, however, were useful in corroborating observations made during the group sessions. For example, in the adolescent sibling group, seven questionnaires were completed, one for each of the regular and irregular participants. Three siblings were rated by their parents as appearing to daydream frequently or sometimes. These were the same siblings who described themselves as escaping from their anxieties sometimes by daydreaming or withdrawing from whatever was going on.

Only two of the participants were rated by their parents as irritable or hostile sometimes. This was

consistent with the observation that the adolescents in the group both felt and expressed less anger than their counterparts in the younger group. In the elementary school age group, four of the five siblings were rated by their parents as being irritable, quick to flare up, and quick to pick up quarrels with others, sometimes. This was consistent with the enormous anger and tension observed and expressed by the siblings in that group.

In the younger sibling group, four of the five siblings were rated as wanting help sometimes when they could have done something on their own. One sibling was rated as wanting help often when he could have been independent. This corroborated the dependency needs and desire for attention the children expressed in the sibling group.

Parents in the younger group reported that all five siblings tried to get along with peers, almost always and joined others freely of their own accord. This rating reflected the young siblings' expressed longing to be with peers, but due to the limitations of the instrument, it did not reflect the reality that the siblings did not have the opportunity to join other children due to the parents' fears and preoccupation with the sick child's illness.

Personal discussions with psychosocial researchers in the field of pediatric illness since this study was initiated, have indicated that other instruments, such as the Reynolds, Richards Manifest Child Anxiety Scale to be

completed by children, and the Achenbach Child Behavior²¹¹
Checklist, to be completed by parents, would have been more
useful instruments for this study.²⁷

NOTES - CHAPTER VI

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CHAPTER VII
EVALUATION

CHAPTER OUTLINE

INTRODUCTION

EVALUATION DESIGN

USE OF EVALUATION FEEDBACK FOR PROGRAM CHANGE

PARTICIPANTS' ASSESSMENT OF THE TWO MODELS OF INTERVENTION

- A. SIBLINGS
- B. PARENTS
- C. THE HEALTH CARE TEAM
- D. DISCUSSION

CHAPTER VII

EVALUATION

INTRODUCTION

This chapter will discuss the evaluation design used in the project and will demonstrate how evaluation was used to refine the program through continuous feedback. Data collected from sibling group participants, their parents and the health care team regarding their assessment of the program will be presented and the implications of their assessment will be analyzed.

EVALUATION DESIGN

This project was exploratory intending "to collect information about a problem, a group or an organization and to explore issues that occur in implementing new strategies."¹ Consistent with the objectives of the project and its innovative nature, the evaluation design focused on process evaluation, i.e. on clearly describing what the project workers were doing and finding. These findings were expected to bring to light important concepts, processes and interactions which deserve future attention in more systematic research and practice.

Several authors have suggested that the most appropriate framework for a program at an exploratory stage, with a high degree of variability and uncertainty is not an outcome evaluation but a formative process

evaluation which serves to refine the program design through frequent communication and feedback.²

Accordingly, feedback was solicited from all the parties affected by the project, the healthy siblings, their parents, the sick children and the health care team.

Feedback was obtained through personal and telephone interviews, volunteered statements, and direct observation. In the sibling group program, group discussion and evaluation questionnaires provided additional sources of feedback. The instruments used to collect data for the descriptive monitoring research which process evaluation entails were discussed in Chapter II. They are reproduced in the appendix.

USE OF EVALUATION FEEDBACK FOR PROGRAM CHANGE

The management of parental anxiety about sibling involvement in the group program offers rich illustrative material for demonstrating how feedback was used to refine the program.

On the whole, parents were extremely responsive to the prospect of their healthy children's participation in the group program. They seemed anxious but not resistant. Their anxiety was expressed in their initial contacts with the investigator in which they sought clarification about the content and purpose of the group program. They also wanted assurance that they would not be blamed if their children criticized them. They further sought a promise

that their children would not be given any publicity.

Voysey, Birenbaum and others have examined the nature and causes of this type of parental anxiety.³

Voysey writes:

"The public appearance of any family member may be taken as evidence of the family's 'state' and given their common identification, the behavior of any one member may reflect on the others. As team managers it is the parents' responsibility to ensure that the proper impression of its individual and joint behavior is sustained. Children, however, are incompetent performers and untrustworthy participants in interaction."⁴

Although these authors discuss disabled children, rather than chronically ill children, the dynamics of the families coping with the stigma of illness are very similar. The parents perceive themselves as "deviant" and strive to protect themselves from the stigma of illness.

Chesler et. al. studied the impact of childhood cancer on a representative sample of 55 families drawn from the total population of children with cancer who had been treated at Mott Hospital in Ann Arbor Michigan over an eight year period. The study focused on the nature and extent of major stresses identified by parents. Investigators found that many parents considered friends, coworkers and extended family members as potential stressors. Chesler et. al. describe the parents' dilemma in "going public".

"One of the critical tasks the parents of a chronically ill child must face is "going

public", sharing the new reality and as much of its meaning as they wish with family and friends. This is a self-redefining action. In its accomplishment the parent informs himself/herself and others of a life changing status he/she and others have just assumed. Uncertainty about the social rules governing the behavior of seriously ill children, concern about how others will react and a desire to give the "right" impression to others all create awkward social situations. As Goffman (1968) notes, people related to a stigmatized person often are treated by others as stigmatized themselves. Moreover they often internalize the same reaction to such stigma. No one likes being labeled or stigmatized and denial or silence about the illness may be a way to avoid further social stress and not just a psychological defense against a threatening disease."

The parents' initial anxiety was also conveyed to their healthy children. After the first two group sessions, group participants indicated that their parents seemed overly eager to know what was happening in the group. The participants felt bombarded with intrusive questions about group process and content. This alerted the investigator to the fact that a structured weekly telephone contact with the parents was desirable in order to alleviate anxiety and identify specific areas of concern. Weekly pre-session telephone calls to parents were therefore instituted. Parents welcomed these phone calls and shared both positive and negative feedback. One mother, for example, was very upset about a specific incident in the group. Her two healthy sons were attending the elementary school age group. The older brother

reported to the parents that in one group session the younger brother drew angry pictures on the blackboard about what he would like to do to his sick sister; pull her hair and break her toys.). "How could the investigator permit such behavior?", the mother asked. The younger healthy sibling was punished at home for his behavior in the group.

This telephone discussion led to a meeting between the pediatric oncology social worker, the parents, patient, and her two healthy siblings. A thorough professional reassessment of family dynamics and adaptation was initiated. Family education regarding the importance of expressing intense feelings in a harmless way was also instituted. This family subsequently needed a referral to a community agency for family therapy. In the meantime, in response to this specific episode, there was a temporary shift in the way time was used in the group and the topic of sibling loyalty was introduced for discussion. Did sibling loyalty mean loyalty to the sick sibling only, or did it also include loyalty to the well siblings? This topic stimulated the exploration of healthy siblings relationships with each other in families that have a cancerous child. Do these relationships change after the diagnosis? How do they change?

The experience of one group members' punishment at home for his activities in the group also forced the investigator to re-examine these activities, and to reevaluate the original decision to forego ground rules of

confidentiality in the sibling groups. In this reevaluation, the reasons for not establishing confidentiality as a group standard were upheld as valid. The sibling groups were not designed as therapeutic groups, with a therapeutic contract between parents, siblings and the investigator. Both parental and sibling anxiety was too high to permit a commitment to confidentiality without the risk of further alienating the healthy siblings from their parents. The risk of parents sabotaging their well children's participation if they perceived the group as a threat to themselves or to their control over their healthy children, was a third consideration.

Siblings were therefore not asked to refrain from discussing the group with parents or others. The feedback from one mother regarding this incident alerted the investigator to one of the unanticipated consequences of the group program if more than one sibling from a family participates in it. The feedback also led to additional clinical intervention for two group members whose family was at risk for maladaptation to the cancer experience, manifested in part through the scapegoating of one of the healthy siblings.

PARTICIPANTS' ASSESSMENT OF THE TWO MODELS OF INTERVENTION

Freeman and Sherwood state: "The evaluation process should include two activities. Description of process and assessment of outcome."⁶ Carter and Wharf point out that

the relative importance of the two activities depends on the type of project that is conducted. "In projects of inquiry using the participant observation method and in projects of exploration, the description of program implementation constitutes the primary evaluative activity. Since these projects are designed to inquire and explore, the main interest is to gain enough information to determine whether the program or method was appropriate and useful."⁷ To gain information about the appropriateness and usefulness of the program from the participants directly, siblings, parents and health professionals were asked to make their own assessment of the program. Carter and Wharf emphasize that such assessment is of necessity subjective and must be accompanied by a thorough description of process in order to be of value. The description of process in this study was presented in Chapters III and V.

Siblings' Evaluation of the Group Program

An evaluation questionnaire was given to each participant who attended the last meeting of each group (see appendix). Participants were asked to assess which aspects of the program they liked and considered helpful. They were asked to specify what they gained from the program and to indicate whether they wished to maintain contact with other group members. Suggestions for improving the program were solicited.

To simplify the presentation of results, Group A will refer to the elementary-school age group. Group B will refer to the adolescent-young adult group.

Five participants attended the last session of Group A, 6 attended the last session of Group B. To provide for the inclusion of all the sibling participants in the assessment of the project, data were also collected from the logs and process recordings of each session and from the observations of the investigator throughout the project. Tables I - IV present a summary of the participants' assessment of the program by Group.

TABLE I

SUMMARY OF PARTICIPANTS' ASSESSMENT OF THE GROUP

GROUP A

Did you enjoy meeting other kids who have a sick brother or sister?

	Number
YES	5
NO	0
TOTAL	5

Would you like to stay in touch with any of the young people you met in the program?

YES	5
NO	0
TOTAL	5

TABLE II

SUMMARY OF PARTICIPANTS' ASSESSMENT GROUP B.

Did you enjoy meeting other kids who have a sick brother or sister?

YES	6
NO	0
TOTAL	6

Would you like to stay in touch with any of the young people you met in the program?

YES	3
NO	3
TOTAL	6

Tables III Group A Participants' Responses on the Aspects of the Program Found Most Beneficial.

TABLE III

The Most Beneficial Aspects of the Program, Group A

	N	Frequency
Learning more about my sibling's sickness	5	3
Learning more about the causes of cancer		4
Learning that no one can catch leukemia		2
Meeting new friends who also have a sick brother or sister		5
Being able to talk about my sick brother or sister		3
Learning that people with the same problems can help each other		2

TABLE IV

Group B Participants' Responses on the Aspects of the Program Found Most Beneficial

Being able to talk openly and honestly with others who are in the same boat	6	3
Gaining a sense of not being alone with fears and doubts in my mind		5
Meeting new and different people who had a lot in common with me		4

Discussion

All the siblings in both groups felt that they benefited from the group experience. The participants' assessment of what they found most beneficial reflected the differences in their ages and developmental needs. The elementary school age children emphasized gaining information about their sick siblings' illness and its causes as one of the major benefits of the program. This is consistent with the 8-12 year old's preoccupation with cognitive mastery.⁸ The older siblings did not mention the acquisition of information as an important gain. This difference may also reflect the fact that young children are dependent upon parents and others for information about cancer whereas older siblings have the capacity to do their own research to obtain the information they need.

The elementary school age siblings' evaluation placed greater emphasis on the benefit of making new friends. This is consistent with their developmental need for friendships and peer group experiences. Adolescents have their own developmental needs for peer group experiences and friendships but they have more freedom and opportunity to seek out these experiences and relationships both at school and at work.

The older siblings' emphasis on the benefits of group interaction and acceptance may stem from the universal adolescent struggle with alienation and

loneliness. It also confirms the notion, derived from developmental theories that in adolescence, "for the first time a resolution of the psychosocial crisis depends not on the relationship of an individual to an adult in the environment but rather on the interaction of an adolescent and peers."⁹

The siblings' responses regarding the least favorable aspects of the program related to termination in the young sibling group and to group size in the older group. Respondents in Group A unanimously wished that the group had not ended. The participants in Group B also regretted that the group ended. They realized that poor attendance was a problem and suggested that monthly rather than weekly meetings could attract a larger group. Three siblings felt that including younger children in the group, ages 8-12 could be of benefit to everyone. These siblings felt that the older siblings could help the younger ones by virtue of their greater maturity. The participants were divided on this issue. Three of the adolescent siblings felt that the presence of younger children would inhibit group discussion. The older adolescents were unanimous in expressing their disappointment about the size of the group. All respondents in Group B wished that the group had been larger. They would have liked to meet more people, and get more ideas and opinions about the topics that were discussed. A 16 year old sibling wrote, "What I liked least about the program was the size of the group. I feel

it may have been more interesting if there was a larger turnout."

Suggestions for improving the program varied. In Group A the majority of siblings wanted to keep the group format and process virtually the same as the one offered. They wanted sessions more than once a week. Three of the five siblings suggested adding more discussion about the causes of cancer. Two siblings recommended more discussion about why cancer affects some children in a family, and not others.

Suggestions from respondents in Group B reflect their greater level of sophistication. Two siblings recommended more structure to the group meetings, specifically the selection of one topic for each meeting. One sibling recommended more focus on the participants' relationships with the sick siblings.

A 16 year old girl suggested taping the sessions of various groups, young siblings, parents, older siblings and patients, using these tapes to promote understanding and empathy between the various groups. This sibling also developed a sensitive, comprehensive plan on her evaluation questionnaire, suggesting ways in which siblings can be better prepared for what lies ahead by listening to tapes of others who have gone through the experience.

Parents' Evaluation of the Group Program

The parents of siblings who participated in the group program were interviewed within three weeks after the program was completed. The majority of parents were interviewed in the clinic when they brought their sick children for appointments. The mother of two of the siblings, who did not accompany her sick adolescent to the clinic, was interviewed by telephone.

A total of eleven parents were interviewed, eight mothers and three fathers. Six were parents of siblings in Group A and five were parents of siblings in Group B.

Parents were asked to describe their own reactions to the program and to describe the ways in which the program benefited or harmed their healthy children.

Specific observations about the consequences of the program either at home or at school were solicited. Suggestions for future sibling programs were invited. The following table presents the parents' responses on the program's benefits for their healthy children.

TABLE VParental Evaluation of Program Benefits - Group A

	N	Frequency
The program made the children feel special: They had a place to go to, a place that was uniquely theirs in the hospital.	6	6
They had a chance to talk about what was on their mind, and to ask questions of the professionals.	6	5
They met other children who were going through the same thing.	6	6
They had a chance to make new friends.	6	6

TABLE VIParental Evaluation of Program Benefits - Group A

	N	Frequency
The program made the children feel special and important.	5	4
They had a chance to talk about what was on their mind, with objective professionals.	5	5
They met other children who were going through the same thing.	5	5
They learned that they were not alone in a difficult situation.	5	4

TABLE VIISummary of the Parents' Assessment of Impact of
the Program Upon Them As Parents - Group A

	N	Frequency
I was glad that something was offered for my healthy children.	5	5
I was nervous at first but then I relaxed.		4
My child loved coming to the group and that made me feel good.		5
I was sorry that my child could not attend every session.		1
My child has been much more cheerful at home since the group started and that made me very happy.		4
Because of the program my husband and I talk a lot more about our healthy child.		3

TABLE VIIISummary of the Parents' Assessment of Impact of the
Program Upon Them as Parents - Group B

	N	Frequency
I was glad that something was offered for my healthy children.	6	6
I was nervous at first but then I relaxed.	6	5
My child loved coming to the group and that made me feel good.	6	4
I was sorry that my child could not attend every session.	6	3
I had a lot of extra driving and juggling to do but that was only for a short time.	6	3
My daughter was disappointed and so was I.	6	1

Discussion

Ten of the eleven parents felt that their siblings benefited from the program. "Feeling special, and having a chance to talk about things on their mind were the most frequently cited benefits." As a group, the parents of the younger siblings were more enthusiastic in their responses. They recognized the group as a vehicle for making friends. They perceived their young children as more deprived as a result of the illness than the parents of the adolescents who viewed their children as more independent and less in need of parental time and attention. This perception was accurate, and was very similar to the way the children and adolescents perceived themselves according to their presentations in the groups.

Only four parents expressed criticism about any aspects of the program. One mother of a boy in the young sibling group questioned the need for spending any time of the group in play. She specifically objected to the fact that her son's clothes were dirty from playing hide and seek after a particularly emotional, tense session. Three of the parents whose siblings' were in the adolescent group were critical of the size of the group. They felt their children would have gained more from the experience if the group had been larger. Suggestions from the parents included having a monthly rather than weekly group sessions. This was perceived as a way of attracting a

larger group, and reducing the burden of transportation for the parents. Specific consequences of the group as observed by parents were so varied that they defy categorization. The consequences observed included, more cheerful behavior on the part of the sibling, less overt jealousy expressed towards the sick child, less demanding behavior exhibited in relations with parents and more frequent discussions initiated by the sibling about activities in the hospital and about the purposes of the sick child's clinic visits. Fewer nightmares, for one of the young sibling group participants and less daydreaming for others. Only one behavioral change was mentioned by more than one parent as a consequence of the program. This change consisted healthy siblings' ability to approach parents more directly about something was troubling them.

For example, one nine year old sibling in Group A who had been embroiled in a provocative, sullen relationship with her father was able to say to her father towards the end of the group program: "I know you worry more about _____ (her two sick brothers) than about me. But can you please find some time to do something with me, and with me alone, at least once." Because the well sibling spoke in a tone which did not imply an angry demand, the father listened and approximately one week later complied with the sibling's request, playing a game with her, a game which only she was old and competent enough to play. Mother reported that

this child's relationship with her father improved markedly as a result of the group. She added that as parents, she and her husband contributed to the improvement since the group helped them to reexamine their treatment of the healthy child in the family.

Parents of the participants in the younger group identified with their children's sense of loss when the group ended. They supported the continuation of the group at least on a monthly basis. The deterrents to such continuation, primarily staffing and transportation problems were discussed with the parents. One mother, upon learning that Medicaid paid for the transportation of the sick children, but would not pay for transportation for the healthy sibling offered to advocate with the government if necessary. She announced during a crowded clinic session, "What does the government want. Does my healthy daughter have to become emotionally sick in order for them to pay? This program could keep my daughter and the other kids in the group healthy by preventing problems. What can we as parents do to change this crazy system?"

The mother of two siblings in the adolescent group also became an ardent supporter of the group program. This mother was initially very hesitant about her children's participation due to the long distance of the family's home from the medical center. After the siblings attended their first group session, and went home excited about what they had gained, this mother who both worked and attended

college at night found a way to drive her healthy children forty miles each way to the rest of the sessions. She indicated that her healthy children informed her that the group enabled them to talk about their brother's illness without feeling defensive or anxious for the first time since their brother became ill.

The Health Care Team's Evaluation of the Group Program

Feedback from the two oncologists, nurses, clinical nurse specialist, social worker, psychologist and social work intern who comprised the health care team was solicited throughout the duration of the program. One month after the groups ended an evaluation meeting was held at which the findings of the project were presented, costs and benefits of the two models of intervention were assessed and the future of the sibling program was discussed.

The following descriptive analysis presents the team members' assessment of the group program.

The program was viewed as a successful, worthwhile project for identifying and meeting sibling needs.

The five team members who attended some of the sibling groups reported that the experience heightened their appreciation of the siblings' need for information, involvement and support.

The groups were perceived as vehicles for keeping siblings psychologically healthy, thereby providing health

professionals with an opportunity to do preventive work. Two nurses offered to continue the program by running sibling groups in collaboration with the oncology social worker. All team members were genuinely eager to find ways to address the siblings' need after the project ended. This eagerness is partly explained by Brunner's observation that "the best way to create interest in the subject is to render it worth knowing."¹⁰

Discussion

Concerns about program efficiency and limited staff availability expressed at the evaluation meeting called for answers to questions recommended by Tripodi, Fellin and Epstein for the evaluation of program efficiency. The questions they consider important address the relative costs of different interventions and the relation of program costs to the benefits achieved.¹¹

This exploratory project was designed to explore questions about siblings' needs and the feasibility and value of developing sibling groups and other family-centered approaches for meeting those needs. The project was not designed to evaluate the cost effectiveness of different models.

Fortunately, the extensive monitoring data collected for the formative evaluation of the project enabled the investigator to present information to the health care team about barriers encountered in implementing sibling groups,

and information about the time expended in developing and implementing two such groups. The investigator's diary, logs, attendance records, records of all activities related to the groups, revealed that for each sibling group, approximately ten hours of work, were expended in addition to the actual time spent by the two group leaders with each group. The extra hours were spent on activities such as letter wrtiting for recruitment of group members, pre and post session telephone calls, room preparation, transportation arrangements, purchase of supplies, etc. In view of the small number of siblings who were reached by the group program, this type of professional investment in weekly groups did not seem fully justified on an ongoing basis. Hadassa Gronfein, Ph.D., of Mt. Sinai Hospital, New York has reported a similar conclusion.¹² A monthly group open to siblings of varied ages may be worth pursuing as a method of providing peer support and professional support to siblings. The present study suggests that the shared experience of having a sick sibling is so powerful that it may provide a basis for communication and interaction between siblings at different stages of psychosexual development. The advantage of a ongoing monthly group would be that its ongoing nature would make it available to siblings whose brother or sister was just diagnosed as having cancer. The period of the initial diagnosis has been described by the participants in this study, as well as by siblings in other studies as the

loneliest, most anxiety filled period of their lives. This period should be one during which health professionals reach out to healthy siblings in every possible way to alleviate the anxiety and loneliness they feel. The disadvantages of a monthly group include the reduced intimacy and openness between members and the limited time available to work through difficult problems and feelings the siblings experience. Dr. Gronfein suggested an additional disadvantage. She found that a mixed age group of siblings tends to discourage adolescents from returning to the group.

The adolescents' struggle with issues of group membership and identity as part of their maturational process, makes it difficult for them to see themselves as members of a group which includes young children. In view of the value of sibling group demonstrated in this study as well as in the limited literature available on the subject, it would appear that the provision of a monthly sibling group should be explored in all hospitals which serve large numbers of pediatric cancer patients.

Conclusion

In the team evaluation meeting, the family-centered approach emerged as the most appropriate model for helping siblings from a resource allocation point of view.

The evaluation of this model will be summarized below.

Three families were studied intensively during and after the cancer diagnosis of their sick child. Data collected about the needs, stresses and changes experienced by the 9 siblings in these families were described in Chapter II. This presentation will focus on the siblings' and parents' responses to sibling involvement in the diagnostic and treatment process of the sick child. The investigator recorded the participants' statements and behavior during hospital and clinic visits. In two cases, collaterals, including teachers and relatives were also interviewed.

The following quotations illustrate the range siblings' and parents' responses to questions designed to probe their emotional reaction to sibling involvement in the cancer treatment process.

Question A: Directed to Siblings In The Clinic

How do you feel about coming to the hospital with _____. (sick child).

Sample of Responses:

"I like coming with him. I like to see what is going on here." (age 10)

"I don't like to miss school but I wanted to see what this place is all about." (age 7)

"It's not bad. My mother and sister are always talking about this place so I wanted to check it out for myself." (age 13)

"I like the toys in the waiting room. But can you promise me that they won't give me any needles today." (age 4)

"It makes me sad to see all these little kids with no hair." (age 12)

Question B: Directed to Parents In The Clinic

Sample of responses to question B: Addressed to Parents:

How do you feel about bringing _____ (the sibling) to the hospital.

"I wanted them to come. D.B. can explain things to them about the bone marrow transplant much better than I can. They probably have a lot of questions they want to ask him."

"I don't mind bringing them. I just hope they don't give me a hard time and make a lot of noise in the clinic. I can't bother with them when I am here."

"They wanted to come so badly. I am glad they had no school so I could bring them. They always want to know what is going on here."

"B. is a big help to me when she comes along. She stays with _____ (the sick child) while she is getting the transfusion and keeps her company. She also keeps her eye on the I.V."

Discussion

Siblings, parents and health professionals responded favorably to this model of intervention. Parents placed

only one clear limit on the timing of the siblings' involvement. The three mothers and three fathers in this sample did not want their healthy children included in the early team meetings during the diagnostic process. They wanted to absorb the information, emotionally and cognitively before they brought the healthy siblings into contact with the professionals. In addition, they were not sure how much information regarding prognosis and treatment risks they wanted the siblings to have before the treatment was initiated.

The parents reluctance to include siblings in this early phase of their relationship with the health care team must be viewed as adaptive rather than pathological when one considers the enormous challenge parents face as soon as they are confronted with the cancer diagnosis of one of their children.

D'Angio et al. capture some of the quality of this early period:

"The parents of a child with cancer are forced to ride an emotional roller-coaster. First they are shocked by the diagnosis, hardly knowing that cancer can affect children, much less their child. The first anxieties stem from the belief that their child will soon be dead, so dreaded is the disease. Their fears are mitigated to some degree when they learn that effective therapy is available and that there is hope for the future, but new worries ensue as the treatment and its concomitant side effects are explained.¹³

The side effects parents and patients must contemplate include both the reversible manifestations of cancer treatment (nausea, hair loss, reddened skin, body changes, as well as the more insidious, possible long term effects such as sterility, cardiac and kidney impairment and loss of mental competence.

Since treatment has to be initiated as soon as possible for optimal effectiveness, parents must weigh the risks and benefits of the treatment recommended, and arrive at a decision regarding treatment while they are still coping with the initial shock of the diagnosis. Involving the healthy siblings in this complex and painful decision making process may be more than what parents can tolerate during this period of intense anxiety and doubt. One mother in the study gave the following account of the siblings' early involvement in the family's crisis. "We told the healthy children that L. has leukemia. They cried. We all cried. The other kids were reassured by the fact that L. will be on a three year treatment protocol. To them, this protocol means that she is expected to live at least three years. If they knew all the things that can go wrong in those three years, they would not have a moment's peace."

The Investigator's Evaluation of Sibling Involvement in the Treatment Process.

"The participant observer shares in the life activities and sentiments of people in face-to-face relationships."¹⁴

McCall points out that one of the strengths of participant observation studies, a strength acknowledged even by many severe critics, is the importance of these studies in generating seminal ideas or explanations which are attributed to the participant observer's closeness to his data.¹⁵ In this study, the investigator's experience as a participant observer led to an observation which may explain why siblings are currently not being seen when pediatric cancer patients receive medical treatment and concomitant psychosocial care. Providing care to pediatric cancer patients, confronts health professionals with an overwhelming emotional challenge. Telling parents that their child has leukemia or some other cancer and that their child may die has been acknowledged as one of the most draining tasks pediatric cancer specialists face.¹⁶ The therapy necessary to induce remissions and to control cancer in children is complex and difficult to tolerate. Children are subjected to frequent and multiple procedures virtually all of which are associated with pain and occasional serious complications. Health professionals see the children's and their parent's pain numerous times in their daily practice. When a child is nearing death, a frequent occurrence in a pediatric center, the levels of anxiety rise for all who are concerned with the child's care. Not only are professionals reminded of their own mortality, but for the physicians, death may also arouse guilt, and a sense of failure for not living up to a role expected of them.

When professionals must cope with patients' parents' and their own anxiety and pain, they have little energy or interest left to think about siblings. In her perceptive analysis of reasons why family treatment is so underutilized in health settings, Kemler suggests that professional self-protection plays a role in opposing family involvement.

"A final issue which cannot be ignored has to do with countertransference, a phenomenon that may account in part for the infrequent involvement of the entire family. It has been this author's clinical and training experience that working with families can stir up potentially more intense feelings than working with an individual. In a setting where intensity of feelings is already high which is certainly the case in hospitals, some resistance on the part of the worker to seeing the entire family is understandable as a form of self-protection."

Three steps must be taken to overcome professional resistance to the inclusion of siblings in the pediatric cancer patient's psychosocial care:

1. Professionals must be educated to view siblings as vulnerable children who are seriously affected by their brother or sister's illness.
2. The siblings' pain and anxiety must be made visible through their personal contacts with the health care team.
3. Professionals must be helped to understand and appreciate the preventive potential of their work with siblings.

It is the author's contention that health care professionals do have the opportunity to prevent burnout through a variety of techniques and supports. They can, therefore, be expected to include siblings in their practice and cope with the additional emotional demands which this inclusion entails.

NOTES - CHAPTER VII

EVALUATION

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CHAPTER VIII
SUMMARY, IMPLICATIONS AND RECOMMENDATIONS
FOR DIRECT PRACTICE

CHAPTER OUTLINE

INTRODUCTION

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CHAPTER VIII
SUMMARY, IMPLICATIONS AND RECOMMENDATIONS
FOR DIRECT PRACTICE

INTRODUCTION

This chapter will summarize the findings of the study, explicate its limitations and discuss its implications for professional practice with families who have a child afflicted with cancer.

SUMMARY

This exploratory study identified eight major sources of anxiety and feelings of isolation for the healthy siblings of cancer patients. These were: emotional realignments within family, frequent separations, overwhelming feelings of anger, burden and uncertainty, feelings of vulnerability, and danger, fear of death and constriction of social life precipitated by the demands of the cancer patient's illness.

The study also tested two potential models of intervention, a family-centered model which included siblings in the diagnostic and treatment process of the sick child, and support groups developed specifically for the siblings. A total of 21 siblings and 17 parents, participated in the study. This population was selected through purposive sampling.

The findings of the study confirm those of several prior studies. The present investigation will be linked to previous research in the sections which follow.

Robin Kramer's exploratory research conducted at the University of California came closest to this investigation in thrust and purpose. A detailed review of her work was presented in Chapter II. The major difference in findings of this study and Kramer's consists of the fact that in this study, the sick child's therapeutic regimen was not as significant a source of stress as it was for the population in Kramer's study.¹ This may be partly explained by the fact that at Hampton Medical Center, the site of the present study, patients and families are helped very early in the treatment process to prepare for, and cope with some of the more troubling physical changes: to cope with hair loss, girls are fitted with attractive wigs and are encouraged to wear them. Boys are encouraged to wear baseball hats and parents are advised to buy matching hats for all the males in the family.

Another difference between the present study and Kramer's consisted of the fact that fear of death represented a significant source of anxiety and stress for the siblings in the present study. Koch-Hattem noted similar findings. Kramer did not identify that fear as one of the major stressors for her healthy sibling population. No explanation is presently available to account for this

difference.

Cairns et al's findings about the prevalence of sibling anxiety and isolation were also confirmed in the present study. Although no psychometric measures were used to compare the scores of healthy siblings and patients in the areas of anxiety and isolation, the study's observations and findings are consistent with Cairns et al's conclusion that "Siblings of children with cancer have significant anxiety, fear for their own health, social isolation and other stresses once thought to be peculiar to the patients themselves."²

Spinnetta's finding that school age siblings of cancer patients (6-12) view their parents as psychologically distant from them was also confirmed in the present study.³ In addition, the study further corroborated Spinnetta's observation that "siblings are often neglected by parents not because their needs are not important, but because they are less important important after the diagnosis."⁴

In a very poignant way, individual siblings both in the sibling groups and in the families studied also demonstrated the validity of Spinnetta's conclusion that, "Siblings of children with a life-threatening illness often face alone the developmental tasks necessary to achieve adulthood. Their attempts to seek help from parents often meet with a plea to be mature and generous and to respect

the needs of the ill child. Even the mentally strong and healthy sibling cannot be expected to go through life's transitional stages without support from parents."⁵

To date, no previous research has depicted as graphically as the present study has, the enormous burden and responsibility some adolescent and young adult siblings feel regarding their sick sibling's physical and mental health.

This is a significant finding in light of the developmental tasks of adolescence which include emotional, and in late adolescence, physical separation from the family as the adolescent establishes his or her identity and experiments with memberships in many groups outside of the family.⁶ Feelings of responsibility for a sick sibling's well being, coupled with practical demands for the adolescent's physical and emotional presence in the family can be expected to interfere with the adolescent's ability to separate himself from the family without undue guilt, to prepare himself for successful adulthood. The study provided several examples of such interference.

ORGANIZATIONAL ISSUES INVOLVED IN THE STUDY

To achieve an intervention such as this in a complex, bureaucratic organizational environment requires considerable strategic and tactical planning. Each part of the organization represents a "busy system", fully involved

in its own primary activities, trying to maintain a sense of stability and balance. Hence, the organization requires an elaborate set of formal (and informal) permissions from senior organizational gatekeepers, none of whom are social workers. In this section we will describe some of the steps that were necessary to take to gain organizational sanction, achieve a modest organizational impact, and obtain some organizational insight that might be transferable to other medical settings where similar interventions could be considered in the future.

Gaining Organizational Sanction

First, steps had to be taken in order to gain formal institutional sanction to conduct a scientific study, and then to ensure the adequate protection of human subjects through evidence of informed consent. The first committee needed to attest to the scientific validity and value of the research design in order to determine whether the intervention would be worthy of formal organizational support. However, since the committee was composed entirely of those trained in medical (or "hard") science, social science experiments generally were not understood or highly valued. The committee's manifest objection to this intervention was that it involved siblings and families, not the actual patients themselves; however, the latent message was that this was not a priority topic for research

because -- in the judgment of doctors, biologists and physicists, this intervention was not scientifically rigorous or prestigious, and therefore not of great interest or value to the institution as a whole. Indeed, the project probably never would have been approved by this committee if there had not been one reasonably sympathetic member who informally advised this researcher of the problem. The former chairperson of the committee (who still had considerable organizational power and prestige) was then enlisted in developing a strategy to "get the proposal out of committee." This was achieved by having the one supportive member explain that social workers consider families as their patients, and thus the formal committee objection should in this case not prevail. Here, however, it was this researcher's strategic use of the informal system that made the formal system respond. Contacts were used and relationships and goodwill with important non-social work influentials "cashed-in" to overcome a seemingly insuperable and certainly unexpected form of organizational resistance.

The lessons from this experience were well learned so that much advance preparation was done to ensure smooth passage through the human subjects review committee. Support from influential members of this committee was explored and lined-up well in advance of the formal presentation of the proposal to the committee. We had

learned what perhaps we should have known: that organizations often resist innovation, especially when it is outside their area of understanding, and suggested by one of the less prestigious and more peripheral units of the organization. The need to deploy informal interventions to influence the formal system was a lesson learned and not to be forgotten.

Second, steps had to be taken to gain informal sanction -- in recognition of the principle that formal sanction is necessary, but seldom sufficient. Despite approval from these formal institutional committees, there needed to be a series of complex informal negotiations with important gatekeepers in the collaborating service (oncology), professions (medicine and nursing), department (pediatrics), and with fellow mental health practitioners (psychologists and social workers). Any one of the above gatekeepers could have placed the experiment in jeopardy by their operational opposition, or even by their withholding of support.

Fortunately, the focus of the Pediatrics Department was very bio-psychosocial, and thus congruent with a social work approach and the experimental model. Pediatrics also had a strong interest in research, a history of willingness to enter into collaboration, and considerable comfort with the notion of family intervention. A well-known and respected social work supervisor was used as a point of

entree, since some of her personal and professional credibility with the pediatric and oncology staff was transferable to the researcher. This supervisor also ran interference with the staff psychologist, who was seen as potentially resistant if not included in the intervention. The suggestion was to give the psychologist responsibility for conducting the diagnostics of the complex cases. This gave her a function (albeit peripheral) so that she would not sabotage the project. However, the tactic kept project control squarely in the hands of the principal investigator, and her chosen team.

The most complex forms of informal sanction had to be won from the core staff of the unit -- the doctors, nurses and social worker. Understandably, they feared that the intervention, however worthy, would further burden an already over-extended service. An exchange had to be offered: that the principal investigator (herself an experienced social worker) would participate directly as a service provider, in exchange for the research opportunity. This would protect (in fact partially relieve) the regular oncology social worker; but more important, it would constitute both a real and symbolic way in which the investigator could "pay her dues". She became "one of them, getting her hands dirty" by becoming a front-line practitioner with her own caseload. A secondary goal of this participant-observer role was for the

researcher to gain the trust of pivotal staff by living with all their pressures and sharing their space. The investigator thereby became a familiar and accepted figure at the clinic, both to the staff and to the pediatric oncology patients' parents, whose support she needed in order to enlist their well siblings in the group interventions. The investigator was also able to develop a series of working alliances with other staff which had considerable pay-off in terms of enlisting their support for continuing elements of the project, after the formal research intervention was completed.

Achieving Organizational Impact

One of the central goals of an organizational innovation should be to ensure some element of lasting impact (after the experimental intervention is completed). However, the creation of change from within is complex and difficult, even when the organizational context is relatively simple and the organizational actors are prestigious and influential. In an extraordinarily complex, highly bureaucratic, multi-disciplinary setting where the investigator is not associated with a central or status profession, the task involves even more of a challenge.

Despite these obstacles, several examples here of ongoing organizational impact can be identified. First,

the institution has formally recognized that family members of the identified patient can legitimately be conceptualized as part of the patient population of the hospital for purposes of intervention. That is, families have become a legitimate unit of service. Moreover, family members of the children in the hospital (who legally are minors) include not just the childrens' parents, but also the siblings. Second, in this context, the pediatric oncology patients' entire families now will regularly and routinely be seen -- not by the entire interdisciplinary team, which would be optimal -- but at least by the oncology social worker on duty. Parents also will get the opportunity, with hospital sanction, to bring in the patients' well siblings as a matter of course, not exception.

Third, the nurse or physician who takes the initial history of new pediatric oncology patients will get the names and ages of the patients' brothers and sisters, and ask key demographic, health and adjustment questions about them to record in the patient-family personal history record. Finally, the medical staff currently is considering the institutionalization of a once-a-month sibling group, to be jointly run by a nurse and a social worker (which we feel, in fact, is the optimal collaboration).

While this impact may seem modest, it does represent a formal change in protocol in each case as a direct result of the experimental intervention. By partializing our goals, we have indeed been able to achieve some outcomes beyond our initial expectation. Greater impact might have been possible if the idea had been suggested from within pediatrics or oncology. Staff might not only have come away with a greater sense of ownership of the innovation; in addition, the innovator would have been able to continue to be on hand to monitor, nourish and support the ideas -- rather than to be seen as "walking away" once the new protocols were in place. Without a matched intervention from within, this hypothesis, of course, cannot be actually tested.

In any event, it is safe to say that both short-run and long-term outcomes of the intervention can be observed. However modest, the ecology on oncology clearly has been changed in favor of the patients, their siblings and their families.

Obtaining Organizational Insight

Many of the lessons to be learned from this research intervention are organizational in nature. While some have been mentioned in earlier chapters, and others may, in retrospect, seem self-evident, they bear further scrutiny and systematic recording.

First, in a complex, highly bureaucratic, multi-professional institution, take nothing for granted -- not even the relatively routine approval by a research or human subjects committee. Second, one needs the unconditional support of one or two central actors with influence or power. A respected department head, an influential chairperson of a gatekeeping committee, a prestigious professional practitioner -- one of these may need to be called upon to "unstick" the process and informally serve as an "organizational rabbi", protecting the unit of intervention. Third, strategic planning must be sufficiently flexible to allow for fallback strategies in response to unanticipated consequences. The usefulness of the theory of contingency management here is very much worth noting.

Fourth, it probably is easier to win support for such an innovative intervention in a major teaching institution, with a strong commitment to research and demonstration, than in a small, unaffiliated hospital that may not perceive the payoff and potential for exchange inherent in such an experimental effort. Fifth, one should carefully plan to make as modest use of scarce existing resources as possible if one hopes to build a constituency and achieve institutionalization of the project. Protocols are not likely to be changed unless one can show that in doing so, the homeostasis of the affected organizational units will not be disrupted, and, the innovation will not

be a burden to staff who will have ongoing responsibility for its administration.

Finally, in an inherently interprofessional setting, the experiment is likely to achieve broadest support if the design is on an interdisciplinary basis. No one profession -- even medicine -- could do it alone. It was ultimately the nursing - social work alliance that was the keystone to the positive outcomes. Given the reality that the core function of a hospital is medical in nature, the collaboration should include medical personnel at every level. (An alliance of social work and psychology, for example, would not likely have been as successful.) Indeed, collaboration between an oncology nurse (with system's sophistication) and staff of the social work department would appear to be an optimum partnership for the form of venture that was undertaken in this project.

While such an experiment always in some measure is dependent on chance, serendipity and good fortune, we have reaffirmed that strategic organizational planning is essential. This observation we feel constitutes a modest yet important element of our findings.

LIMITATIONS OF RESEARCH

The following limitations of the research should be considered in interpreting the findings. The limitations fall into three categories: nature of the sample, size of the sample, and methods of data collection.

1. Limitations that Pertain To The Nature Of The Sample

The use of purposive sampling for both the family-centered and sibling group models of the study led to samples whose demographic characteristics were not representative of the demographics of the national sibling population as a whole. For example, minority, i.e. black and hispanic children and adolescents were overrepresented in both models of the study. This conclusion is derived from the 1980 U.S. census report which shows that 77.6% of all children aged 3 - 14 in the U.S. are white, 14.0% are black and 8.4% are hispanic. In the 15-19 age group, 78.9% of adolescents are white, 14.0% are black, and 7.1% are hispanic.⁷ In the study population of siblings, only 20% of the siblings were white, 25% were black and 55% were hispanic.

At the same time, siblings living in single parent households are underrepresented in the study. Only two of the 21 siblings who participated in the study lived in single parent households. This is a significant bias in light of the fact that according to the latest census report 22% of all children in the U.S. under 18 live in single parent households.⁸

Hamovitch who studied the effects of a Parent Participation Program in improving the coping capacities of

82 leukemic children and their families found that single parent families and parents who were remarried had the greatest difficulty in coping with their child's illness and death. This finding is readily understood when one considers the enormous emotional, physical and financial burdens a child's fatal illness imposes on the parents. Without a partner who feels committed to share that burden, the demands of the illness must seem almost insurmountable.

The present study demonstrated that many siblings in two parent families feel very deprived due to the parental preoccupation with the sick child. It is foreseeable that a healthy sibling who only has one parent is likely to feel even more deprived and abandoned since the single parent bears the full responsibility for the sick child's care and treatment. It is also likely that in single parent families, healthy children are expected to assume a parental role in order to relieve the single parents at least occasionally. In the present study, this observation was made about the sibling group participant who at 17 was expected to act like a father to his sick sister.⁹

2. Limitations That Pertain To The Size Of The Sample

Although adequate for an exploratory study which sought to gain insights about the phenomenon of sibling needs and potential models for meeting these needs in the field of pediatric cancer care; the small size of the

sample limited the investigator's ability to study and analyze variables such as socioeconomic status, religion and availability of extended families which have been shown to have a bearing on familial responses to stress.

The nature of the sample, and the small size of the sample prohibit the generalization of findings to siblings and families with other demographic characteristics. In Davidson's words: "Since the samples were small and non-randomized, generalizations beyond the sample groups must be made cautiously and the implications drawn from the study need to be viewed as tentative."¹⁰

3. Limitations That Pertain To The Method
Of Data Collection

Participant observation has been used as the principal method of data collection for this study. Although many researchers sanction the use of participant observation in exploratory studies, they also point out that observational techniques are subject to editing and are influenced by such factors as observer attitude and anxiety.¹¹ For this study, several steps were taken to reduce editing and increase reliability. These measures were discussed in Chapter II. Even with these safeguards, however, the reliability of the findings is affected by the problems of inference and proof inherent in the use of participant observation as a method of study.¹²

IMPLICATIONS FOR PRACTICE

Despite the limitations cited above, when the findings of the study are combined with available research evidence and theoretical knowledge, described in Chapter II, certain compelling practice implications emerge:

Health care professionals and community agencies must enhance and supplement the pediatric cancer patients' parents' ability to meet the emotional and social needs of well siblings in the family. The well siblings' needs are age-related, i.e. affected by the sibling's stage of development. They are also affected by how well the family has met the sibling's needs in previous stages of development prior to the onset of the disease.

In addition to age-related sibling needs which must be assessed individually for each family whose sick child is treated for cancer, the siblings of pediatric cancer patients have certain universal needs which arise from the stresses and disruptions imposed by the family's experience with a life-threatening illness.

These universal, special needs include:

1. The need to be loved and to be recognized as important members of the family even during periods when parental preoccupation with the sick child relegates them to a position of less importance.

2. The need for accurate disease-related information.
3. The need to be included in the communications and activities of the family.
4. The need for parental permission to engage in age-appropriate social activities both inside and outside the home.
5. The need to have opportunities to express feelings and fears about their sibling's illness, and to receive emotional support as they cope with a lot of upheaval, uncertainty and change in their lives.

Sibling support groups represent one model for providing those opportunities and meeting those needs. They are, however, very time consuming to implement and their utilization is adversely affected by geographic limitations.

Professional insistence on early and regular meetings between the entire family and the health care team can also help provide those opportunities and meet those needs more economically and appropriately. Parents are likely to express initial hesitation about bringing their healthy children to the hospital until they have had an opportunity to process the information about their child's catastrophic illness and to develop trust in the health care team. The findings of this study and the work of

Lansky and Ross strongly suggest that professionals who are convinced about the importance of working with the entire family, communicate that conviction to parents who will then cooperate.¹³

Review of the literature did not reveal any studies or clinical efforts in which parents who have been invited to link their healthy children with the health care team have refused to do so. The literature review did reveal several studies which reported on the guilt and regret some parents experience as a result of giving less attention to their healthy children.

The physical, emotional and practical demands of the illness place parents in a "no-win" position with respect to their healthy children. Burton conveys the parents' dilemma succinctly in her study of families coping with cystic fibrosis. "The mother's overall stress was accentuated when she was forced to choose between being with her sick child or remaining at home with his well brothers and sisters. Whatever choice was made, inevitably she felt neglectful."¹⁴ Meahrig calls for professional attention to the parents' dilemma.

"Professionals should not overlook the feelings parents have about the attention and time they devote to different children. Much guilt can be aroused or they alternately feel resentful that the healthy children make demands upon them when they are already tired from caring for the handicapped child. Even when parents look at their situation objectively, they still must face a major dilemma. There is only so

much time in a day and non-disabled children can do more for themselves. But less interaction with parents can produce feelings of neglect on both sides. Opportunities for healthy children can be limited by their staying home and helping to care for the disabled child as well as by financial resources being devoted to this child's needs. There are no easy or right answers to such conflicts but professionals must be very sensitive to parents having to cope with yet another dimension of the disability on a day-to-day as well as long term basis."¹⁵

The present study identified several specific areas in which professional intervention could enable parents to more effectively meet the needs of their healthy children.

The principles of preventive psychiatry provide the underpinnings for these recommendations for professional intervention. One of the strategies in primary prevention is that of stressor management. "This involves classifying stressors into those that are not changeable and will have to be endured, and those stressors that are potentially changeable."¹⁶ With this framework in mind, it is possible to look at the sources of anxiety and isolation identified in this study, and listed in Chapter V. Each factor listed as a source of anxiety and isolation can be conceptualized as a stressor. Hollister describes stressors as "stimuli that may threaten our survival, threaten our emotional security, defeat our expectations and or overwhelm our coping abilities." ¹⁷

The evidence from this study suggests that each of the stressors noted, is subject to some modification, in varying degrees, if health care professionals make sibling needs a target of their concern.

The recommendations below outline how this might be accomplished:

Stressor I

1. Emotional Realignment Within The Family:

By seeing the entire family, including all the healthy siblings within the first month of the initial hospitalization, professionals can be in a position to influence type of realignment that occurs within the family. Kaplan has demonstrated that "optimal period for intervention is during the early acute stage of the crisis immediately following the confirmation of the diagnosis when the family is making those decisions associated with maladaptive coping and poor stress outcome."¹⁸

Theoretical and research literature in the fields of family therapy and family medicine provide evidence of the effectiveness of treating the family as the unit for intervention.¹⁹ This literature also provides various models which health professionals can use for promoting the

family's capacity for meeting the emotional needs of all of its' members, and for preventing the development of dysfunctional diads and triads in the family system. ²⁰

By extending interest to the healthy siblings in all contacts with the parents during ongoing treatment, health professionals have a continued opportunity to modify the emotional realignment between family members. Asking questions such as "what did Janie get when Bruce received his new fire engine?" can raise the parents' consciousness about what is happening in the family. Encouraging parents to change a clinic appointment or postpone a procedure if it interferes with a significant event in the healthy sibling's life, redirects parental attention to the sibling's needs and conveys the health care team's view that the sick child's needs do not always supersede the well sibling's needs.

STRESSOR II

Feelings Of Vulnerability And Danger:

Factual information offered to well siblings by health care workers both in person, and through the provision of literature, can eliminate needless fears and give siblings answers to worrisome questions.

The siblings' fear of radiation treatments, identified in this study can be addressed prior to treatment, thereby preventing needless anxiety. Assurance about the non-familial nature of cancer, e.g. assurance to girls that their own children will not automatically be at risk for cancer and that they are not at risk themselves, is another area in which feelings of vulnerability can be modified. Practitioners as well as researchers have found that "information reduces uncertainty and eases the threat of the unknown."²¹

STRESSOR III

Fear Of Death

This may be a difficult anxiety to alleviate although there is reason to believe that information, reassurance and the opportunity to express fears could provide certain relief. Adams points this out very clearly.

"When a child is a long term survivor, it is crucial that the physician utilize the opportunity provided by the cessation of treatment to reinforce his belief that the child will live a long and healthy life, if in fact he believes that this is the case. I believe that as long as they feel well physically and emotionally, children can get the most out of their lives no matter how long they live. Children have an amazing ability to achieve more than adults believe is possible especially if they are given a chance to release their anxiety about their illness and prognosis."²²

Although Adams' comments refer to patients, they are equally applicable to siblings. A strong relationship with the health care team could also play an important role in modifying the siblings' fear of death. The entire pediatric cancer literature suggests in concert with the findings of this study that siblings would feel less helpless and alone in their fear of death if they had a relationship with the health care professionals who are active partners in their sibling's battle against death. The crucial support and comfort patients and parents derive from their relationship with the health care team has been well documented.²³ The present study provides reasons to believe that siblings would derive similar support and comfort if they were given the opportunity.

Periodic planned meetings with the entire family will enable the health care team to assess what is happening in the family, and to intervene if necessary. Spinnetta et al demonstrated why such assessment and intervention is so vital.

"In summary, a family spends a large amount of its energy attempting to keep itself from becoming disorganized and disintegrated under the overwhelming threat to the life of one of its members. In the process the family finds itself with little energy left to fulfill its primary function as a support system to each of its members. Individual members may find their own needs unmet. Family members must communicate their needs at a level that can be

understood by others in the family. Unless this communication occurs and individual family members continue to receive support from the family system, the viability of the family unit will be compromised. The goal of working with the families of children with a life threatening illness is to help them strengthen their own adaptive capabilities and coping styles. The health care professional treating the child must take into account family structure and environment. (Van Eys 1977). To help family members use the support system they will need during the remaining months of years of their child's life and after the child's death is the goal for which the professional dedicated to the care of the total child must strive."²⁴

STRESSOR IV

Separations

During a sick child's hospitalization, health workers are in position to help families develop plans which will be the least traumatic for the healthy siblings. The study's example of helping a father keep two young siblings at home with the help of neighbors rather than send them off to a distant aunt represents but one small example of the way parents can be helped.

The separations imposed upon the healthy siblings can also be modified in other ways. Visiting opportunities for siblings in hospitals can and should be expanded. Concerns about infections and disruptiveness which healthy siblings may cause cannot be ignored, but these risks must be balanced against the benefits of enabling the well siblings to remain involved with their sick sibling and

mother who characteristically sits vigil at the hospital. Even after visiting hours are liberalized, parents may need financial assistance and other practical help to facilitate the well siblings' transportation to the hospital.

Encouraging parents to bring their healthy children to the clinic on specific days can also modify the separation well siblings experience when they are shut out from a significant part of their sick sibling's life.

Sloan Kettering hospital's recent introduction of a "sibling day" once a month, represents one model for making siblings feel part of the sick child's hospital world.²⁵

STRESSOR V

Overwhelming Feelings Of Anger, Burden And Uncertainty

The expression and acceptance of these feelings in family meetings with the healthy care team can at least alleviate the burden and explosiveness of the siblings' feelings.

Kellerman vividly describes the benefit families derive from well planned comprehensive psychosocial care:

"Children and families have been very receptive to the notion that stress such as that brought about by a diagnosis of cancer raises psychological vulnerability and families have been accepting and appreciative of psychosocial care when it is presented in this context. Of particular value has been the opportunity to familiarize families with the normal disease-related patterns of stress reaction.

Parents are grateful to learn for example that transitory reactive depression during the initial post-diagnostic period is normal. Providing such information during early psychosocial intervention helps prevent needless worry and provides a frame of reference. It assures the parents and children that what they are feeling is normal and by extension acceptable. Thus rather than increasing feelings of stigmatization, psychosocial care can serve an opposite role, that of normalization."²⁶

Isolation From Family Members And Peers

STRESSOR VI

Isolation From Family Members:

This stress can be modified through influencing the emotional realignments within the family, as discussed previously. It can further be modified through increasing the sibling's participation in the sick child's hospital world.

Redirecting the parental attention to the well siblings can also be expected to reduce the feelings of psychological distance which siblings, especially young siblings feel in relation to their parents.

STRESSOR VII

Isolation From Peers

This stress which primarily affects preschool and elementary school age children who depend on their parents for transportation, planning and supervision of their peer activities, can only be modified if a large array of

accessible, safe, inexpensive community services and programs are made available to the well siblings.

The sick child's vulnerability to infection and illness caused by his immunosuppressed status during active phases of cancer therapy constitutes a formidable deterrent to peer activities in the home. Therefore the young healthy siblings of cancer patients must rely on community resources such as afterschool programs, youth centers, and summer day camps as sites for their socialization.²⁷

Health professionals who work with the families of pediatric cancer patients must take the initiative in educating community agencies about the vital role they can play in meeting the social, emotional needs of healthy siblings.

To facilitate the well siblings' utilization of socialization opportunities offered, community agencies will need to reach out to families of fatally ill children and institute certain non-traditional supports such as escorts, scholarships and transportation which take into account the limited physical, emotional and financial resources parents of fatally ill children possess for engaging in activities which are not related to their sick child's life threatening illness.

A precedent for this type of community education has been established by Victims Service Agency (VSA) of New

York. In its "Helping Children Cope Program," VSA conducts on-site workshops and in-service training for educators and community groups with the goal of sensitizing them to the needs of children faced with the death or abduction of a friend or classmate.

RECOMMENDATIONS FOR FUTURE RESEARCH

The recommendations discussed above call for research testing regarding effectiveness. Prospective large scale studies of siblings who are included in a comprehensive family-centered treatment program of pediatric cancer patients, matched with a control group of siblings who receive no support or attention from the health care team would yield valuable data about the relative effectiveness of the comprehensive approach in facilitating the adaptation of well siblings. Such research would also yield needed information about the psychological and social costs of excluding well siblings from the pediatric cancer patient's care.

Research on the needs and vulnerabilities of well siblings in single parent families of pediatric cancer patients emerges as an urgent priority from the present study. Sibling studies to date, including the present one, have used two parent families in their samples thereby excluding siblings who are likely to suffer most from lack of parental attention, inadequate resources, and age-inappropriate burdens.

The third area of research which emerges as a priority is the replication of existing studies. Sibling research which is still in its infancy has been justly criticized for methodological weaknesses. These weaknesses include small samples and diverse and scattered efforts in which the concepts used were often not the same, the observations of data were not commensurate, and the samples studied and methods used were not replicated across disciplines.²⁸

This criticism must be addressed before sibling research can be truly useful for theory construction and modification of existing health care practices. "Repetition of results is the basis of scientific generalization."²⁹

Spinnetta's rigorous landmark research which used operationally defined concepts, standardized instruments as well as specifically constructed instruments to study, patients, families and siblings in a variety of settings and disease-related circumstances calls for replication and has potential for gaining the attention and scientific respectability which the siblings of children with a life threatening illness deserve.

The present study explored the causes of sibling anxiety and isolation and demonstrated that the siblings and parents who participated in the study were receptive to professional intervention and support which addressed the needs of the pediatric cancer patients' siblings.

It is hoped that the findings of this study will encourage researchers and practitioners to include the well siblings in their consideration when they design and deliver medical and psychosocial services to pediatric cancer patients.

The two models of intervention employed in this study also have applicability to siblings of patients with other life-threatening illnesses, such as cystic fibrosis and chronic kidney disease. The study also suggests that the family, the health care team and the community must share the responsibility for the support of these vulnerable siblings. The parents of a child who has cancer are engaged in a relentless battle against the death of their sick child. Professionals in health care facilities and community agencies must join them in this battle in order to reduce the casualties.

The families of childhood cancer patients must be supported in a flexible way by a combination of many possible community resources. Without those additional external supports, the siblings of cancer patients will continue to be added to the casualty list.

NOTES - CHAPTER VIII
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A P P E N D I X A

Letter Of Introduction and Consent Form
To Be Given To The Parents Of Siblings
Who Will Be Invited To Participate In
The Sibling Group

The Social Service and Pediatric Departments of Montefiore Hospital are conducting a study of the needs of the siblings of pediatric cancer patients in order to learn more about ways in which siblings can receive the support they need during a time of stress for the entire family.

We are inviting all school age siblings of the Pediatric Hematology/Oncology Clinic patients to meet in a group with a professional social worker once a week for 8 weeks. At the meetings, the children will have the opportunity to discuss their questions, feelings and concerns about their brother's or sister's illness and their experiences in coping with their friends' and family's reactions to their sibling's illness and treatment.

The purpose of the group is twofold:

1. To provide more information to health care professionals about the concerns, fears and needs of siblings.
2. To offer special attention and support to siblings. It is anticipated that the siblings will benefit from talking and relating to other siblings, all of whom share the common experience of having a sick brother or sister.

Research evidence has shown that the siblings of sick children can feel alone and worried through no fault of anyone.

It is our hope that this group may alleviate some of these feelings of loneliness and anxiety and help the siblings learn new ways of coping with the stressful role of the well sibling.

Your son's or daughter's participation in this group is entirely voluntary. You may refuse to participate in this study or discontinue your child's participation in this study at any time without prejudicing in any way your child's further treatment or your relations with the hospital, its doctors or its staff.

You have the opportunity to ask any questions you wish regarding the purposes and procedures of this study.

Letter of Introduction and Consent Form
To Be Given To The Parents of Siblings Who Will
Be Invited To Participate In The Sibling Group

If you have any questions about the study and would like to meet the social worker who will be leading the sibling group, please contact Mrs. Bendor at 920-4401. Also, the staff of the Pediatric/Hematology/Oncology Clinic is aware of this study and you are encouraged to discuss it with your child's pediatrician and social worker.

If you agree to your child's participation in this study, please sign the accompanying consent form.

I, _____, hereby agree to have my child, _____, participate in the sibling group for the siblings of pediatric cancer patients.

Signature

Date

Telephone #

5/7/86
sb/nb

Carta de Presentacion
y consentimiento para ser
entregada a los padres de los
hermanos que serian invitados a
participar en el grupo fraternal

Los departamentos de Servicio Social y Pediatria del Centro Medico Hampton estan llevando a cabo el estudio de las necesidades de los hermanos de los pacientes diagnosticados de cancer, con el proposito de saber mas acerca de las maneras en los cuales los hermanos pudieren recibir la ayuda que necesitaren en los momentos de "angustia familiar".

Estamos invitando a todos los hermanos en edad escolar de los pacientes de las clinicas de Hematologia (de sangre) Pediatrica y Oncologia (de cancer) a reunirse en un grupo con asistente sociales profesionales una vez a la semana por el lapso de 8 semanas. En estas reuniones los muchachos tendran la oportunidad de discutir las preguntas, sentimientos y preocupaciones acerca de la enfermedad de sus hermanos y sus experiencias en ajustarse a las reacciones de sus amigos y familia en relacion a la enfermedad y tratamiento de su hermanos enfermos.

El objetivo de el grupo es doble:

1. Proveer mas informacion a los profesionales de la salud sobre las preocupaciones, ansiedades y necesidades de los hermanos de estos pacientes.
2. Ofrecer especial atencion y apoyo a los hermanos. Se anticipan que los hermanos se beneficiaran al hablar y relacionarse con otras hermanos, que comparten la experiencia comun de tener un hermano enfermo.

Evidencia científica establece que los hermanos de pacientes enfermos se pueden sentir solos y preocupados, sin que esto sea causado por madre en particular.

Es nuestro deseo que este grupo pudiere alivian algunos de estos sentimientos de soledad y ansiedad y ayudarse a estas hermanos a aprenden nuevas vias de ajustarse con el rol estresante de ser el hermano sano.

La participacion de su hijo (a) en este grupo es enteramente voluntaria ud. puede reusar a participar en este estudio o descontinuar la asistencia de su hijo (a) en esta actividad en cualquier momento sin que prejuicio de cualquier especie en el tratamiento futuro de vuestro hijo (a) enfermo (a) sus relaciones con el hospital, los medicos o el personal.

Usted tiene la oportunidad de hacer todo tipo de preguntas que desee en relacion a los objetivos y procedimientos de este estudio.

Si Ud. tiene cualquier pregunta acerca del estudio o desea conocer el asistente social que dirigera el grupo, por favor contacte a la Senora Susana Bendor al telefono (212) 920-4401; Tambien el personal de las clinicas de Hematologia Pediatrica y Oncologia esta al tanto de este estudio y le pedimos que Us. discuta con ellos este estudio.

Si esta de acuerdo en la participacion de su hijo
(a) en este estudio, por favor firme el formulario de
consentimiento.

Yo, _____, consiento que mi
hijo (a) _____ participe en el
grupo de hermanos de pacientes pediatricos
diasnosticados de cancer.

Firma

Fecha

Telefono

CHILD AND ADOLESCENT ADJUSTMENT PROFILE
(CAAP SCALE)

Name of Youngster Being Rated

Your Name

1. Today's Date _____
Month Day Year

2. Your Relationship to Youngster (Check one)

1. _____ Mother (stepmother, foster mother)

2. _____ Father (stepfather, foster father)

3. _____ Teacher

4. _____ Counselor

5. _____ Other (please specify) _____

3. Sex of Youngster (Check one)

1. _____ Male

2. _____ Female

4. Age _____

5. Grade in School _____

INSTRUCTIONS:

- A. Please describe this youngster's behavior as you have observed it during the past month by answering each question.
- B. Please answer all questions on this and the reverse page, even though you may feel somewhat unsure of some answers.
- C. Mark your answer to each question by making a check () in the box under the "Answer Choices" like this.....|____|

DURING LAST MONTH, HAS HE/SHE... (Please answer each statement below)		Answer Choices			
		1 Rarely	2 Some- times	3 Often	4 Almost Always
1.	Tried to get along with others?				
2.	Joined others freely of own accord?				
3.	Invited others to play with him/her?				
4.	Laughed and smiled easily?				

DURING LAST MONTH, HAS HE/SHE... (Please answer each statement below)		Answer Choices			
		1 Never	2 Rarely	3 Some- times	4 Often
5.	Wanted help in things he/she could have done on own?				
6.	Became discouraged when attempted something on own?				
7.	Asked for help when could have figured things out?				
8.	Asked unnecessary questions instead of working on own?				

DURING PAST MONTH, HAS HE/SHE... (Please answer each statement below)		Answer Choices			
		1 Never	2 Rarely	3 Some- times	4 Often
9.	Flared up if couldn't have own way?				
10.	Become upset if others did not agree with him/her?				

11. Picked quarrels with others? ☐ ☐ ☐ ☐
12. Not responded to discipline? ☐ ☐ ☐ ☐

DURING PAST MONTH, HAS HE/SHE... (Please answer each statement below)	Answer Choices			
	1 Rarely	2 Some- times	3 Often	4 Almost Always

13. Worked hard at tasks or assignments?	☐	☐	☐	☐
14. Stayed with work or assignment until finished?	☐	☐	☐	☐
15. Made full use of abilities?	☐	☐	☐	☐
16. Done work carefully?	☐	☐	☐	☐
	☐			

DURING PAST MONTH, HAS HE/SHE... (Please answer each statement below)	Answer Choices			
	1 Never	2 Rarely	3 Some times	4 Often

17. Sat and stared without doing anything?	☐	☐	☐	☐
18. Done things very slowly?	☐	☐	☐	☐
19. Appeared indifferent and uninterested in things?	☐	☐	☐	☐
20. Daydreamed?	☐	☐	☐	☐
	☐			

Thank you for providing the information requested.
Please check back to make sure you have not missed
answering any questions.

If you would like to make any comments about the
person you have rated, please use the opposite
section for this.

COMMENTS:

Perfil de Adaptacion en ninos y adolescentes
(Escala CAAP)

Nombre del Joven a evaluar

Su nombre

1. Dia de la Fecha _____
 Mes Dia Ano
2. Cual es su relacion con el Joven (marque una)
 1. _____ madre (Madrastra, Madre sustituta)
 2. _____ Padre (Padraastro, Padre sustituto)
 3. _____ Maestra
 4. _____ Consejero
 5. _____ Otro (por favor especifique) _____
3. Sexo del Joven (marque uno)
 - (1) _____ Hombre
 - (2) _____ Mujer
4. Edad _____
5. Grado en la escuela _____

INSTRUCCIONES:

A.

Por favor describa la conducta de este joven de acuerdo a como Usted la ha observado durante el mes pasado respondiendo cada pregunta.

- B. Por favor responda todas las preguntas de esta página y el reverso, y piense que puede sentirse algo inseguro/a frente a algunas preguntas.
- C. Marque su respuesta en cada pregunta, así
En uno de los casilleros que elija, así.....

DURANTE EL ULTIMO MES, EL o ELLA HAN..... Por favor responda a cada pregunta de abajo		RESPUESTAS			
		1 RARAMENTE	2 ALGUNAS VECES	3 FRECUEN- TEMENTE	4 CASI SIEMPRE
1.	Trato de estar junto con otros?	☐	☐	☐	☐
2.	Se junto con otros libremente y de acuerdo?	☐	☐	☐	☐
3.	Invito a otros a jugar con el/ella?	☐	☐	☐	☐
4.	Rio y sonrio con facilidad	☐	☐	☐	☐
		☐			

DURANTE EL ULTIMO MES,
EL/ELLA HAN.....
Por favor responda a todas las preguntas

5.	Quiso ayuda en cosas que el/ella podria haber hecho solo/a?	☐	☐	☐	☐
6.	Se sintio desalentado cuando intento hacer algo por si mismo?	☐	☐	☐	☐
7.	Pidio ayuda cuando podria haber terminado cosas solo/a?	☐	☐	☐	☐
8.	Hizo preguntas innecesarias cuando podria haber trabajado por si mismo?	☐	☐	☐	☐
		☐			

DURANTE EL ULTIMO MES, EL/ELLA HAN.....
 Por favor responda a todas las preguntas

9. Se encolerizo
 (enojo) si no pudo
 lograr lo que queria? ☐ ☐ ☐ ☐
10. Se sintio triste si
 los otros no
 estuvieron de acuerdo
 con el/ella? ☐ ☐ ☐ ☐
11. Tuvo altercados con
 otros? ☐ ☐ ☐ ☐
12. No respondio a la
 diciplina? ☐ ☐ ☐ ☐
- ☐

Por favor responda
 a cada pregunta de abajo

13. Trabajo mucho en
 tareas or
 asignaciones? ☐ ☐ ☐ ☐
14. Permanecio con tareas
 o asignaciones hasta
 terminarlal? ☐ ☐ ☐ ☐
15. Hizo total uso de
 habilidades? ☐ ☐ ☐ ☐
16. Hizo trabajos
 cuidadosamente? ☐ ☐ ☐ ☐
- ☐

DURANTE EL ULTIMO MES, EL o ELLA HAN.....
 Por favor responda a cada pregunta
 de abajo

17. Se sento y miraba sin
 hacer nada? ☐ ☐ ☐ ☐
18. Hizo cosas muy
 despacito? ☐ ☐ ☐ ☐

19. Parecia indiferente y
desinteresado en las cosas? ☐ ☐ ☐ ☐
20. Suenos diurnos? ☐ ☐ ☐ ☐
- ☐

Muchas gracias por proveer esta informacion. Por favor controle nuevamente las respuestas para estar seguro de no haber dejado sin responder alguna.

Si usted desea hacer algun comentario sobre la persona que ha entrevistado, por favor use la carilla opuesta para esto.

LETTER OF INVITATION TO PROSPECTIVE
ADOLESCENT GROUP PARTICIPANTS

Dear _____,

It is my pleasure to invite you to the first meeting of brothers and sisters at Hampton Medical Center on Wednesday, May 2, 1984 at 7:30 p.m. in the Klau 1 Conference Room (see directions below).

The meeting will bring together adolescent and young adult brothers and sisters of patients who attend our Pediatric Hematology Clinic.

It is part of a study conducted by the Social Service and Pediatric Departments of Hampton Medical Center. The study seeks to learn more about ways in which siblings of pediatric cancer patients can receive the support they need during a time of stress for the entire family.

The purpose of the group is twofold:

1. To provide an opportunity to siblings to talk to other people their age, all of

whom share the common experience of having a sick brother and sister.

2. To provide more information to health care professionals about the concerns, fears, experiences and suggestions of siblings.

I will lead the meeting and look forward to seeing you all.

If you have any questions, or need help with transportation please call me at 920-4401.

Sincerely,

Susan Bendor

nb
enc.

Directions of Klau 1 Conference Room

Enter through the main entrance of the Medical Center. Make a left before Coffee Shop. Go through Klau Corridor (Red Zone) to double doors. Go through double doors. Conference Room 1 on right.

GROUP PROGRAM FOR SIBLINGS OF CANCER PATIENTS

(To be Modified by the Responses and Needs
of Group Members)

Session I

Introduction of Group Members to each other.

Description of the Group Program and its purpose, giving participants the opportunity to influence its content and sequence.

Session II

Visit from key Pediatric Oncology Personnel welcoming siblings and describing their own function in the hospital.

Session III

Engagement of Group Members in a discussion of their own experience with a sick sibling.

Session IV

Discussion of members' perceptions of their sibling's illness and its impact upon them.

Session V

Audio-visual presentation of cancer as an abnormal growth of cells, not caused by anyone, not contagious, etc.

Session VI

Description of the treatments and clinic experiences from which well siblings are usually excluded.

Discussion of side-effects of treatments.

Exploration of Group Members own reactions to these side effects.

How do outside people, friends, neighbors, etc., react to cancer and its treatment.

How do group members handle the questions and reactions they encounter.

Session VII

Discussion of member's own feelings about what is happening in their own lives.

What can each member do with the feelings and needs he has.

Role playing of difficult situations members describe.

Session VIII

Summary of Group Themes.

Listing of stresses siblings described.

Acknowledgment of Group's contribution to the education of medical personnel.

Evaluation of Group and plans for future.

S. Bendor
5/86

Group Member Questionnaire

Basic Information

1. What is your name? _____
2. How old are you? _____
What grad are you in school? _____
3. How many brothers and sisters do you have?
Brothers _____ Ages: _____
Sisters _____ Ages: _____
4. How old is your brother or sister who comes to
this hospital for treatment?

5. Please list your activities:
After school: _____
After work: _____

S. Bendor
5/86

Participant Evaluation of Sibling Group Support Program

We want to ask you some questions about the group program. There are no right or wrong answers. We are interested in your ideas and opinions about the program. Please be honest in your answers. Your ideas will help us plan good programs for the brothers and sisters of sick children in the future.

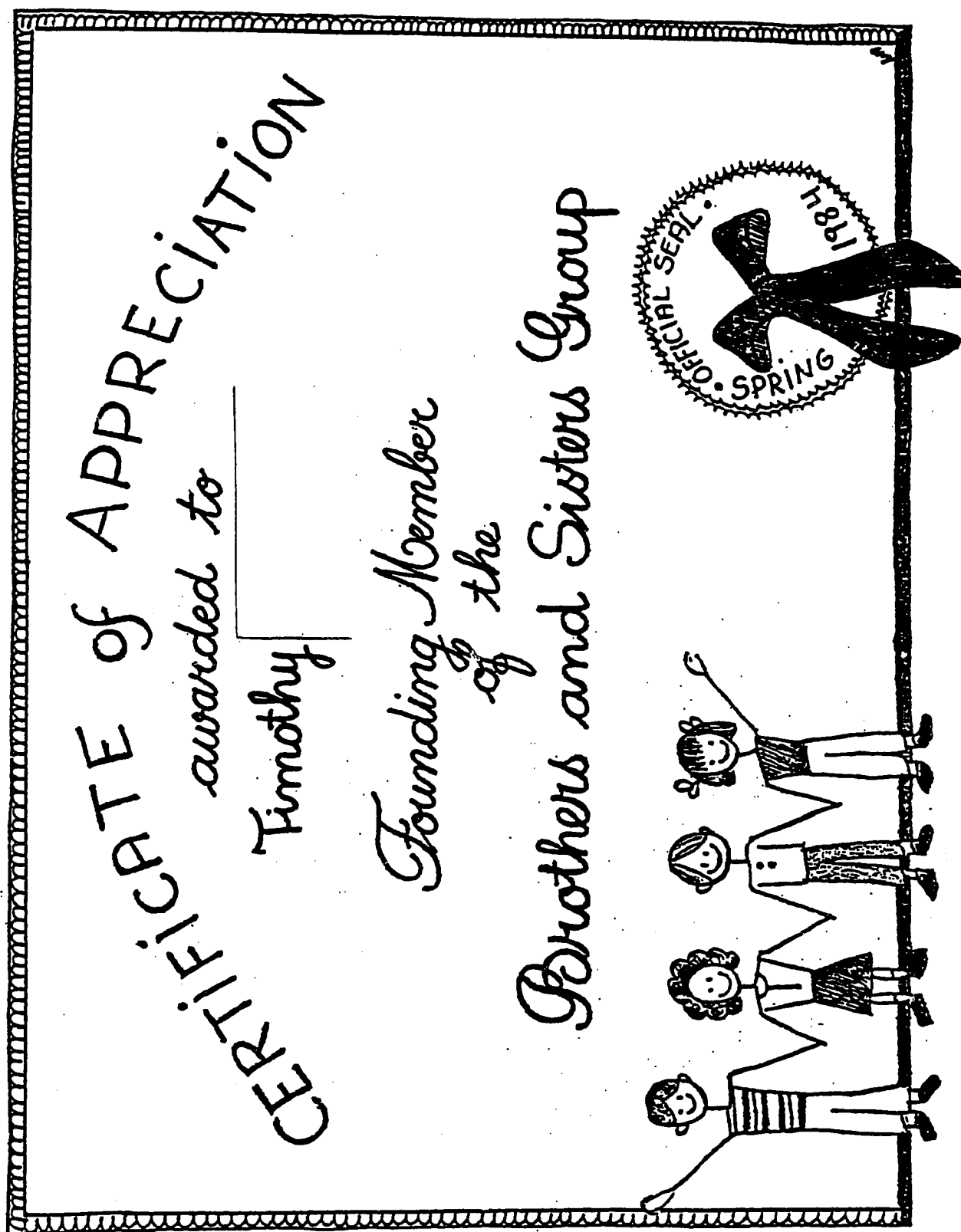
1. What did you like best about the program?

2. What did you like least about the program?

3. Did you enjoy meeting other kids who have a sick brother or sister?
YES _____ NO _____
4. Would you like to stay in touch with any of the kids you met in the program?
YES _____ NO _____
5. Did you have enough time to talk about the things that have been bothering you since your brother or sister got sick?
YES _____ NO _____
6. What if anything did you learn in the program?

7. What suggestions would you make about this program for the future?

S. Bendor
5/86



SCHEDULE A

MODEL IFAMILY INTAKE INTERVIEW SCHEDULE A

Date of patient's admission to the hospital_____

Date of interview_____

I. IDENTIFYING DATAA. Family Composition

Name_____

Birthdate_____

Birthplace_____

Permanent Residence_____

Duration of Permanent Residence (in years)_____

School Grade_____

Siblings:

Names_____

Sex_____

Birthdates_____

Birthplace_____

School Grades_____

Permanent Residence_____

Current Residence_____

Parents

Father:_____

Age_____ Birthplace_____

Current Residence_____

Ethnic Group_____

Religion _____

Education (highest grade) _____

Occupation (current) _____

Employment Status _____

Gross Income per month _____

Mother:

Age _____ Birthplace _____

Permanent Residence _____

Current Residence _____

Ethnic Group _____

Religion _____

Education (highest grade) _____

Occupation _____

Employment Status _____

Gross Income per month _____

Extended Family

Family's reaction to the diagnosis:

Patient _____

Mother _____

Father _____

Siblings _____

Others _____

Information shared with siblings about the diagnosis

Who communicated the information _____

Family Relationships:

Marital_____

Parents to Patients_____

Parents to siblings_____

Siblings to parents_____

Close relatives or others in the home_____

Neighbors and other social relationships_____

Effects of patient's hospitalization on family life

II. Overview of Patient immediately prior to and after hospital admission:

A. Situation at time of intake:

Medical situation_____

Diagnosis_____

Prognosis_____

Treatment plan_____

B. Social Situation:

Person accompanying patient to the hospital_____

Preparation of siblings for the patient's admission

Visiting pattern of mother, father, siblings during the initial hospitalization_____

Frequency of visits_____ Quality of visits_____

Who accompanies the siblings?_____

When they visit_____

Family understanding of the medical condition_____

Mother_____

Father _____

Siblings _____

Others _____

SCHEDULE B

SUMMARY OF CHANGES DURING PATIENT'S TREATMENT SCHEDULE B

Medical Treatment - Summarize pertinent medical treatment.

Social Treatment - Indicate number and nature of social service contacts with family members, including content of contact.

Changes During The Study Period:

- A. Changes in medical situation: Note remissions, relapses, readmissions, surgeries, major and minor - frequency of clinic visits and hospital admissions.

Also note pertinent changes in child's medical condition: e.g. reactions to treatment: symptoms, etc.

Note pertinent changes in siblings' behavior, attitudes, feelings expressed: relationships with patient, parents, school performance, peer relationships, work habits and patterns, reactions to the health care team.

APPENDIX B

APPENDIX B

This appendix contains information on films, books and booklets which were useful in the study and have relevance for professionals interested in working with siblings of cancer patients.

Films:

Childhood Cancer; Siblings Speak Out: available for purchase or rental from Children's Hospital - Oncology Department - 1056 East 19th Avenue, Denver, Colorado 80218.

This is a powerful, poignant film in which several siblings of varied ages, preschool, elementary school and high school are interviewed on film about their experience with a child's cancer. The film conveys their anxiety, sadness, and pain about the changes in their lives, and their feelings of "being left out." The film is an excellent tool for sensitizing health professionals to the impact of the illness on siblings, and for stimulating the interest of hospitals and community agencies in developing support services for siblings.

Although the film has been shown to parents in one hospital to heighten their awareness of the healthy children. In the investigator's view, the film is too anxiety provoking for parents or siblings. It may arouse

too much guilt in parents, and may arouse too much anxiety or anger in siblings. The film's major value lies in its potential for heightening professional awareness of the importance of addressing the needs of siblings in pediatric medical practice.

"Coping With Cancer: The Sibling Perspective: available for rental from the Department of Social Work, Sloan Kettering Cancer Center, 1275 York Avenue, New York, New York 10021.

This tape utilizes a discussion format in which four siblings, ages 6, 9, 12, 16, reflect on the impact of childhood cancer on family, social and school life. The social worker who leads the discussion focuses on the issue of the children's coping with the illness, rather than on their pain.

Coping strategies which are not effective are identified, followed by a discussion of more adaptive coping mechanisms. The tape concludes with some reflection on the positive aspects of the cancer experience.

This film can be used for professional audiences, as well as for patients, parents and siblings. It can be used effectively for stimulating discussion in any one of those three groups.

Booklets:

When Your Brother or Sister Has Cancer, by Laura Rudolph, MSW.

This paperback booklet, containing many illustrations is available upon request from the American Cancer Society. The booklet is designed for children who are grade school age to early adolescence. The book seeks to inform siblings about the common reactions of brothers and sisters to a child's cancer, and to encourage them to express and accept their confusing feelings. Parents are encouraged by the author to read the book with their children and to discuss it. The book informs parents about the common reactions of siblings, thereby preparing them to expect some of the sibling anxiety and anger they are likely to encounter.

The booklet is reassuring in the way it universalizes the cancer experience, and alleviates common worries and fears. The siblings in this study recommended that the book would be most useful to siblings at the time of diagnosis, when they are left alone a lot and have no information about what to expect. Routine distribution of this booklet to siblings at the time of diagnosis would enhance their self-esteem, sense of control, and sense of being included in the hospital experience.

Emotional Aspects of Childhood Leukemia, A Handbook For Parents, written by John J. Spinnetta, Patricia-Deasy Spinnetta, Faith Kung and Donald Schwartz. This booklet is available free from the Leukemia Society of America.

This is a very readable, helpful booklet which is designed to enable parents to cope with the illness experience in a psychologically healthy manner. It addresses a wide range of issues, which parents must confront; e.g. Talking About The Diagnosis, Communication Between Home, Hospital and School, Helping The Patient, and His Brothers and Sisters Cope With The Illness and Get the Most Out of Life. The booklet is practical and reassuring, without being condescending. It can give parents a sense of mastery and can sensitize them to the needs of all their children.

Coping With Childhood Cancer: Where Do We Go From Here?, written by David W. Adams and Eleanor J. Deveau, Reston Publishing Co., Reston, Virginia, 1984.

This hard-cover book is a useful addition to every health care worker's library. It can be lent to parents at appropriate times. The book is full of useful, readable advice and exploration, ranging from what to tell patients and siblings about the cancer diagnosis, based on their ages, to helping patients and siblings prepare for death. The book also contains sections on how to manage anxious grandparents, how to accept help from caring neighbors,

etc. The book provides intelligent, simple explanations for many of the questions which plague parents as they attempt to adjust to their child's life-threatening diagnosis. The book has a hopeful tone, and conveys respect for parents' abilities to cope while accepting their feelings of helplessness and anxiety. I have lent the book to several parents who found its prescriptive style helpful and comforting.

"Hospital Days Treatment Ways": Hematology-Oncology Coloring Book.

This coloring book is available from the United State Department of Health and Human Services, National Institutes of Health, NIH Publication, No. 81-2085, reprinted November 1980.

It depicts pediatric cancer patients in common hospital scenes: e.g. receiving radiation treatment, x-rays, chemotherapy, bone scans, blood transfusions, etc. The coloring book is widely used for young cancer patients to help them adjust to the hospital and to familiarize them with some of the procedures they will experience or witness in the hospital environment. The coloring book can also be used for siblings for the same purpose. It will help young siblings feel more informed about what their sick brother or sister is going through, and will give the siblings an opportunity to ask questions or express feelings or ideas. It can also prepare them for

some of the changes they might see in their sick brothers or sister. For example, in this study, the pictures of children who were bald or wearing a cap or wig in the hospital coloring book, led many of the siblings to ask why the patients looked so funny. This initiated an age appropriate explanation about the body changes which accompany the treatment of cancer. Thus prepared, the siblings in the study were less shocked when their brother or sister came home without hair as a result of the radiation therapy.

The coloring book is an excellent catalyst for important communication with siblings. It also enables young siblings to feel part of their sick brother or sister's hospital world even when they are not allowed to visit frequently due to their young ages. The book also contains pictures of hospital experiences such as eating in bed, talking to the nurses, etc. so that it can be used with very young siblings without the risk of evoking fears or destructive fantasies.

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