ALTERING MOOD IN CHILDREN WITH CANCER THROUGH INTERVENTION WITH THEIR HEALTHY SIBLINGS

By

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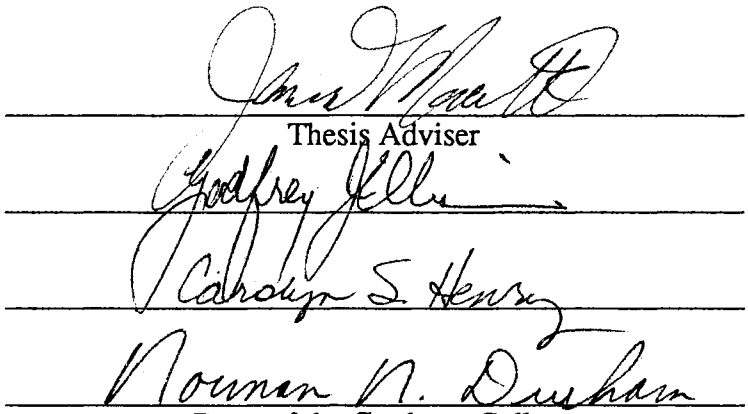

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Abstract

There is a growing awareness among health care professionals that the psychosocial needs of siblings of children with cancer are met at a level significantly less adequate than those of other family members . As part of a larger research study of 17 families of children with cancer, 20 healthy siblings, ages 3-11 years (7 males and 13 females) were tested using the Kinetic Family Drawing-Revised (Spinetta, McLaren, Fox, & Sparta, 1981) in one of two oncology clinics in a southwestern state. Nine of the subjects participated in a Sibling Day. Data from the drawings and discussions with siblings confirm previous sibling research findings, as well as reflect current social changes that will ultimately increase the importance of the sibling relationship itself.

Childhood Cancer: Siblings Draw and Tell

"Cancer: a malignant growth of tissue, usually ulcerating, tending to spread and associated with general ill health and progressive emaciation; a malignant evil that corrodes slowly and fatally." (Webster, 1959, p. 120). An old definition, yet one that even thirty years later frequently serves as the basis for initial emotional responses to the word "cancer." Is it any wonder that news of such a disease in a family member would be sufficient cause for crisis in the family system?

When the family member with cancer is a child, the fact seems even more tragic, disrupting the natural order of life where the old suffer and die and the young carry on the work of the living. Yet, advances in treatment have resulted in dramatic improvements in life expectancy for children diagnosed with cancer. The cure rate for children who develop acute lymphocytic leukemia, the most common form of childhood cancer, has increased to 68%. The average survival rate twenty years ago was three to four months. Hodgkin's disease, almost always fatal in 1960, now has an 88% cure rate (American Cancer Society, personal communication, October 5, 1988). It is estimated that by 1990, 0.1% of all adults (1:1000) will be cured patients who had cancer as a child (Miller, 1988).

The enormous improvement in cure rate of childhood cancer has shifted its classification from a "fatal disease" to "chronic, life threatening disease" (Van Eys, 1985). Although the outlook for today's child with cancer is considerably brighter than in the past, these children experience repeated hospitalizations and outpatient visits, months of chemotherapy, painful procedures, changes in appearance, lack of energy, and frequent absences from school. The demands of the disease, as well as the prognosis, are unpredictable elements families must deal with on a daily basis.

Long recognized as a stressor, chronic or life threatening illness affects all members within the family system (Hill, 1949). The impact of the diagnosis of cancer in childhood ranges from disruptive to catastrophic for the family as the family system and its members struggle to readjust or respond to the change in one of its members (Schlorlemer, 1988). The family's vulnerability to crisis depends upon the interaction of the stressor event with the family's existing resources and their perception of the event (McCubbin & Patterson, 1983). Not only the patient, but all family members experience the crisis, long-term impact, and contingencies of cancer.

While childhood cancer can be devastating for a family, it is important to remember that the diagnosis does not remove the family from the world in which it existed before diagnosis. Nondisease related stressors and their contingencies continue to act on family members. Particularly for siblings of families today, unresolved and new nondisease stressors may cause more distress than those stressors resulting from having a brother or sister with cancer. A comprehensive approach to sibling intervention considers nondisease as well as diseased related stressors.

Sometimes termed "the forgotten ones," siblings are, by most recent accounts, the most left out and unattended to of all family members during the experience of serious childhood illness (Spinetta, 1981a; Chesler & Barbarin, 1987). At the time of diagnosis, it is probably accurate to say that, at least to some degree, all siblings feel left out. Family, friends--even professionals--focus on the ill child and the parents. Siblings are frequently overlooked in the process (Laker, 1988). Thus, it is not surprising that healthy siblings were identified as the most unhappy members in one third of the families interviewed in a recent study of chronically ill children (Tritt & Esses, 1988).

Studies indicate that drastic changes may occur in the healthy sibling's relationships with parents and the ill sibling. Some of these changes result from the demands of the disease itself. The sick child becomes the focus of parental attention and

concerns, resulting in a shift in family dynamics. Family organization and roles change. Ill family members do not complement the rest of the family as they use to: "An ill member is 'out of tune,' unable to contribute to the family in his/her usual way, or is making new demands on the family" (Siemon, 1985, p. 27). Frequent family separation caused by repeated hospitalizations and trips to the medical center for treatment is one of the most disrupting and stressful consequences healthy siblings face. The well children find themselves pushed to the background, often staying at the homes of family and friends. Long distances and strict hospital rules may interfere with visitation (Kramer & Moore, 1983).

Demands of the disease and therapeutic regimen disrupt normal family routines and may interfere with holiday celebrations, vacations, and social interactions. Healthy siblings may resent this intrusion in their lives that frequently demands self-sacrifice (Kramer & Moore, 1983). Parents may be unable to attend the siblings' school functions, ball games, or other activities (U.S. Department of Health and Human Services, 1986). Parents, in their own struggle to adapt, are often physically and emotionally unavailable for the healthy siblings (Kramer, 1981; Sourkes, 1980; Kramer & Moore, 1983). The family's financial resources as well as emotional resources may be directed toward the child with cancer. When this occurs, there is often not only in a decrease in normal family activities, but a decrease in personal items for the healthy sibling as well (Trahd, 1986).

Many of the difficulties siblings encounter in childhood cancer are a result of the nature of the sibling relationship itself. It is within the sibling subsystem that children learn to share, compete, and compromise with others close to them in status. Healthy siblings lose their equal relationship with the disabled brother or sister. "Healthy siblings yearn for someone with whom they can tell their secrets, play, and talk about their parents" (Trahd, 1986, p. 192). Illness places constraints on siblings when love and

competition have been part of their ongoing relationship. Because one member is ill, siblings are no longer able to compete, at least temporarily. Furthermore, there are often feelings of love and positive caring between siblings (Powell & Ogle, 1985; Sourkes, 1986). When love for one another can only be expressed by long distance phone calls or an occasional visit in a hospital room, it may not come as easily (Chesler & Barbarin, 1987). Siblings feel this loss even more in a two-child family, the most prevalent size in America today.

Siblings are often treated differently than the ill child. The ill child receives preferential treatment, with parents tending to be lenient in discipline as well as overindulgent and overprotective (Cairns, Clark, Smith, & Lansky,1979; Kramer & Moore, 1983). This may lead to resentment and jealousy. In interviews with 27 siblings of chronically ill children, 39 percent reported feeling jealous of the ill child (Tritt & Esses, 1988). Siblings sometimes resent having to sublimate their personal needs for those of the child with cancer (Trahd, 1986). Sourkes (1986) reports an additional source of resentment for older siblings: Themselves deprived of attention from parents, older siblings may resent stepping in as surrogate parents for the younger siblings.

Identification, common to sibling relationships, can also be a source of concern. Because siblings often identify with one another and link their fate with one another's experiences, the well sibling may feel responsible for the child's illness. Sourkes (1986) notes that because siblings see many similarities between themselves and the patient, the fear of becoming ill with cancer runs high among siblings. Past experiences that affected one child often affected other children in the same family. Siblings, using projection, think that an illness that could befall one child could just as easily befall another (Sourkes, 1980; Spinetta, 1981a; Chesler & Barbarin, 1987). This is especially true when the siblings cannot stipulate, either cognitively or emotionally, a cause for the

illness. "The apparent randomness of events lead the siblings to think, 'Why not me, too?'" (Sourkes, 1986, p. 20).

Studies report strains in relationships with peers (Iles, 1979; Kramer & Moore, 1983). Not knowing what to say or fearing that cancer is contagious, friends may avoid the sibling. Out of fear or ignorance, siblings are sometimes taunted about their brother or sister's condition. Insensitive comments such as "Your brother is going to die," are not uncommon (Chesler & Barbarin, 1987). Teasing often occurs about the appearance of the child with cancer who may be bald from treatment or "puffy" from steroids. Many siblings report being torn between their loyalty to the ill child and the desire to avoid stigma (Chesler & Barbarin, 1987). Choosing between loyalties can amount to a no-win situation. This confusion frequently causes healthy children to become angry at themselves, their brother or sister, and their friends (Trahd, 1986, p. 192). Perhaps the cruelest of blows occurs when parents of peers restrain their children from playing at a house where someone has cancer. Playmates may disappear for the healthy siblings as well as for the child with cancer (Sourkes, 1986).

Siblings in families of children with cancer are under substantial stress that may result in escalated anxiety, an increased sense of isolation, and fears about their own health problems (Cairns et al, 1979). A healthy sibling's reaction to having a brother or sister with cancer is sometimes evidenced in behavior or adjustment problems, more common in siblings of children with special needs than in their peers where all children in the family are healthy (Gallo, 1988). Problems noted may be minor or severe: enuresis, headaches, poor school performance, school phobia, depression, severe separation anxiety, and persistent abdominal pain (Binger, Albin, Feurestein, Kushner, Zoger, & Mikkelsen, 1969). Sourkes (1986) reports that physical problems, sleep problems, and proneness to injury are common to siblings of children with cancer, possibly as a means of getting parental attention. There is also evidence that some

children will overachieve in school, perhaps as a method of capturing attention (Sourkes, 1986). Or maybe--much like the father who immerses himself in his job--siblings, too, have discovered a means of coping. Many of these problems are fairly common and can indicate that the sibling is having trouble dealing with the situation (U.S. Department of Health and Human Services, 1986).

There has been a recent shift from a focus on psychopathology and disturbance in the sibling to positive adaptation (Sourkes, 1986). A growing number of reports reveal that survivors of childhood cancer (children who survive their illness and parents and siblings of these children) often grow in ways neither we nor they can predict. For example, families indicate they have drawn together, relied on each other in new ways, and love and care for each other more strongly and overtly (Chesler & Barbarin, 1987). Sibling of children with special needs are often very compassionate and sensitive, develop excellent problem solving abilities and coping strategies to use in later life (Powell & Ogle, 1985). Families also report that some siblings experience an increased acceptance of the range of human differences, a less casual attitude toward good health, positive feelings of being responsible for helping their brother or sister, and an understanding of how to communicate effectively with family members and community professionals (Rothery, 1987).

In an effort to meet the demands that a diagnosis of cancer places on the family system and its members, often very little attention is diverted to investigate other nondisease related stressors of importance that may be causing problems in the sibling's life. Nondisease related stressors, coupled with an unavailable ill sibling and unavailable parents, may add to an already high level of stress. A recent divorce or remarriage of a parent, a move, a new baby, a new school, a bully, an alcoholic parent--have the potential to produce equal and in some cases greater levels of stress, particularly for siblings, than disease related stressors (Rollins, in press). Because a

sibling may react to nondisease related stressors with similar behavior or adjustment problems, it may be inaccurately assumed that a sibling difficulties are all a result of having a brother or sister with cancer.

This study attempts to gain some understanding of siblings of children with cancer through analyzing drawings of their families. It is expected that for some children the cancer will be a predominant theme, for others, however, it may not be. For some, other stressors may be more importnat and for others, the families will be seen as healthy and well-functioning regardless of the diagnosis of cancer. This type of study will serve as a starting point for further analysis and understanding of the coping strategies for family members dealing with cancer.

Method

Sample

As part of a larger research study of 17 families of children with cancer, 20 siblings, ages 3-11 years, were interviewed in one of two oncology clinics in a southwestern state. Seven males and 13 females were represented in the sample. At the time of the study, all of the families had a child receiving treatment for cancer at one of the clinics. One clinic was in a general acute care hospital, the other in a children's hospital. Siblings were invited to participate in one of three sibling day programs. Each program consisted of a session to relate information about cancer and its treatment, a tour of the treatment facility, an age-appropriate film dealing with sibling issues, refreshments, group discussions, and a group art activity. Participation in the research project was not a prerequisite for attending sibling day activities, nor was participation in the activities a prerequisite for participation in the study.

Instrument

One of the instruments selected for the study was the Kinetic Family Drawing Test-Revised (Spinetta, McLaren, Fox, & Sparta, 1981). The tool was chosen because

drawing is typically viewed by children as non-threatening, and, in most cases, enjoyable. It has long been assumed that the figure drawn is a unique expression of a child's experiences and preferences (Machover, 1949). Children, particularly young ones, usually express themselves more naturally and spontaneously through actions rather than through words (DiLeo, 1983).

The Kinetic Family Drawing (K-F-D) or Kinetic Family Drawing Test is a projective technique to be used with interviews and other therapeutic techniques. The K-F-D provides information about how children perceive themselves in their family setting (Burns & Kaufman, 1970). Burns and Kaufman began by simply asking children to draw the members of their families doing things. Kinetic (action) drawings were found to be more informative than those obtained from the traditional akinetic instructions. The addition of movement to the akinetic drawing helps mobilize a child's feelings not only as related to self concept, but also in the area of interpersonal relations (Burns & Kaufman, 1972).

Spinetta et al (1981) developed a carefully structured and situation-limited administration and scoring procedure for interpreting the kinetic family drawings of children with cancer and their family. Drawings of adults and children 6 years and older can be scored using this procedure. This specific procedure precludes chance and/or the problematic tendency to overinterpret drawings. In their three year study of twenty-three families with a child with cancer, a correlation was performed between KFD-R scores and Family Adjustment Scale scores (Spinetta, 1981b). The results lent support to the validity of the KFD-R as a measure of a family member's subjective response to the cancer experience. On the issue of reliability of children's drawings over time, Spinetta et al refer to Machover's statement that the examination of a series of drawings over time by the same individual demonstrates constant structure and form, although content

may vary. Thus, while clothing, details, and accessories (content) may change, the size of figures, lines, and placement (form) remain stable (Machover, 1949).

Procedure

Families were invited to participate in the study and the sibling program by mail, phone, or personal contact during a clinic visit. The nature of the research was explained, and questions about the study and sibling program were answered. After obtaining parental consent, the study was explained to the child. A separate child consent form was given and read to each child. Children either signed or marked consent.

Children were tested in a comfortable room a short distance from the general clinic area. The KFD-R was then administered in standard fashion, although felt tip markers were used rather than colored pencils. A sheet of plain white 8 1/2 by 11 inch paper and a package of 10 colored markers (red, yellow, light blue, dark blue, orange, purple, brown, black, light green, and dark green) were placed in front of the child. Although all the children were asked to draw, only those produced by children 6 years and older could be scored using the KFD-R scoring system. An effort was made to obtain at least three drawings from each child. Within the scoring system used, low scores indicate more adaptive (i.e., healthier) families. See Appendix B for instructions for obtaining a Kinetic Family Drawing and scoring protocols.

Results

Design

Given the low sample sizes, a case study approach to the data was chosen. Of interest were the findings indicating nondisease related stressors. Certainly all children's responses were individualized and unique. Five cases are selected here for detailed description as somewhat representative of those children and their families in relation to the diagnosis of cancer in a brother or sister.

Group discussions plus the children's drawings confirmed much of what is known and documented about siblings of children with cancer. But, in particular, the individual drawings and follow-up explanations by the children revealed the importance of exploring additional concerns when assuming a family-centered approach to care. All names have been changed to protect the confidentiality of the families.

Case study 1: The Green Family. The Green family consists of Mrs. Green, Scott, age 7 years, and Timmy, aged 6 years. Scott was 5 years old when his brother Timmy was diagnosed with acute lymphocytic leukemia. The boys' parents had divorced 6 months earlier. Now, 2 years later, Timmy's leukemia is in remission and he seems to be doing quite well. Mrs. Green is in her late twenties and works full time outside the home. Timmy's grandmother usually brings him to the clinic. Scott almost always accompanies them. On observation, there appears to be a warm relationship between grandmother and both of the boys.

Scott appears to be a shy child, a sharp contrast to his outgoing younger brother. Quiet, yet polite, he will answer questions, but doesn't elaborate or volunteer information. Through his drawings, however, Scott "tells" how he is likely feeling (See Figure 1).

Insert Figure 1 about here

Under the KFD-R scoring system, Scott's drawing received 10 out of a possible 16 points on the subscale "Communication." An important feature noted was the fact that everyone is in a compartment separated by lines, comprising barriers between family members. Mother (by Scott's report) is lying down, and both Timmy (the

patient) and the mother have their backs to the viewer. Scott omitted major body parts: Mother is hidden in her chair, Timmy's legs are incomplete, both boys are missing hands. Scott partially crossed out Timmy when labeling him in the drawing (name covered due to confidentiality), and drew himself with his back to the viewer. It is interesting to note that the mother is smaller than the children and Timmy, the youngest, is drawn as the largest member of the family. A total score of 8 out of a possible 9 points were assigned on the "Self-image" subscale. On the final subscale, "Emotional Tone," Scott's drawing received 4 out of 10 possible points. Scott chose to use only one (black) of ten available colors, and gave himself no facial features. Scott's total KFD-R score was 22, high on Spinetta et al's negatively valenced scale, representing a maladaptive drawing. (See Appendix C for scoring details.)

On this particular occasion Scott seemed to be somewhat depressed, yet unable to verbalize his feelings. When asked about his drawing he said simply, "Mom is watching TV, I'm playing a video game, and my brother is flying a kite." In looking at the drawing, it appears that Scott is feeling very little communication between family members. Timmy seems to be the biggest and most important member of the family (Timmy portrayed himself the same way in his family drawings). Mother may be perceived as unavailable for Scott and perhaps Timmy, too.

During the sibling day activities Scott was cooperative, but very quiet, speaking only when spoken to. While Scott talked very little about the meaning of his drawing, he produced two similar kinetic family drawings over a six week period, all scoring within the same range. Timmy's drawings, though more adaptive than Scott's, also indicate a lack of communication between family members. It was Timmy, however who gave a clue to another family issue: Their father had recently announced his intent to remarry. The family was referred to the clinic staff for follow-up.

Case study 2: The Johnson Family. There are 4 children in the Johnson family: 13-year-old Sam, 10-year-old Karen, 6-year-old Sally, and 2-year-old Jennifer. The three older children are from Mrs. Johnson's first marriage. She remarried 3 years ago and Jennifer is a product of her second marriage. Sam was diagnosed with acute lymphocytic leukemia 3 years ago during the Johnsons' first month of marriage. At the time of the study his leukemia was in remission and he was due to go off treatment within the next few months.

Mrs. Johnson is unemployed and devotes her time and energy to her family. She speaks of the guilt she felt over the x-rays she had when pregnant with Sam and, as newlyweds, how difficult it had been at the time of Sam's diagnosis. Her new husband was and continues to be very supportive. He, too, seems to enjoy family life. In his spare time he built a backyard playhouse, the subject of many of the children's drawings.

Sally, second to the youngest, is bubbly and full of energy. The backyard playhouse is the scene of her first family drawing.

Insert Figure 2 about here

Sally's drawing scored 2 points on the subscale "Communication." She placed barriers between some of the family members, and excluded her baby sister, Jennifer. In the subscale "Self-image," of note are the lack of feet and hands on more than two people, minor cross-outs on all of the family members except herself, missing body parts (feet and hands) on herself, and incorrect size of family members. Her total for this subscale is 6 points. Additionally, in her drawing she used a stickfigure to portray her

stepfather, and omitted the nose on her face. Her combined score totals 10, representing a fairly adaptive drawing. (See Appendix C for scoring details.)

An interesting feature of this drawing is the color Sally chose to draw Sam (the figure to the far left in the drawing). He is the only family member drawn in brown. In Sam's first family drawing, brown was the only color used. Children will often use the color brown to express pain. Klepsch and Logie (1982) define brown as an expression of regression. On the day that both Sally and Sam's drawings were produced, Sam was at the clinic for a spinal tap. At the risk of overinterpretation, could Sally's drawing actually be expressing understanding of Sam's circumstances at that particular moment? When discussing Sam, Sally and 10-year-old Karen said he is frequently angry and "mean." The girls said he never talked about having cancer and suggested that maybe being sick is what makes him mad.

Karen said that in the beginning she felt Sam's leukemia was her fault. She admitted this for the first time during the sibling day discussion. The facilitator asked, "Often brothers and sisters tell me that they think its their fault their brother or sister got sick. Have any of you ever felt that way?" The children all looked at each other and first one, and then another began nodding yes. When all but a few had joined in, there was an almost audible sign of relief that at last the guilt had been expressed. As time has passed and Karen learned more about Sam's condition, she is now "pretty sure" that she is not responsible for his illness.

As mentioned, Jennifer was omitted from this drawing and a third family drawing Sally produced. Ten-year-old Karen also omitted Jennifer from her first drawing. On observation, Sam seems to have a very special relationship with his half sister, and is very willing to help his mother with Jennifer's care.

This family has experienced a great number of significant changes over the past three years, any one in itself a sufficient cause of stress. Within one year the family

added two new members (stepfather and baby sister) and is faced with the threat of losing a member. It appears that some family members are still struggling to adapt to the many changes in the family. A new equilibrium will eventually be reached. If dysfunctional patterns develop they may or may not be permanent (Hoopes & Harper, 1987). While it typically takes 9 months for the child and family to adapt to the change in life style that the diagnosis of cancer may institute (Hall, Hardin, & Conatser, 1982), it may take some time longer for this family system to reach a new equilibrium, especially if accompanied by other significant life events.

Case study 3: The Stevens Family. This was a second marriage for both Mr. and Mrs. Stevens. Mrs. Stevens is employed, while Mr. Stevens attends a vocational training school. When they married 5 years ago they each brought to the union 4-year-old sons, Darryl and Donald. Now 9 years old, Darryl--Mr. Steven's natural son--had been diagnosed with osteosarcoma of the right arm five weeks before. While his step brother Donald was attending a sibling program at the clinic, Darryl was upstairs in the hospital's oncology unit. Doctors were deliberating over whether or not Darryl's arm would be amputated the following day.

Donald's drawing received no points on the subscales "Communication" and "Emotional Tone" under the KFD-R negatively valenced scoring system. In the subscale "Self-image," Donald partially crossed-out the figure he designated himself, and depicted his parents as smaller than himself. Donald's final score totalled 3, indicating an adaptive drawing. (See Appendix C for scoring details.)

Insert Figure 3 about here

Additional information, however, was obtained on Sibling Day. Donald was finally able to verbalize his concerns during the group discussion segment. Another sibling was telling about her younger sister with cancer and how difficult life had been for the family. At school the sibling's classmates would tease her and tell her that her sister was a freak. At this point in the discussion a small quiet voice from the fringe of the group--a voice we had only heard a word or two from all day--announced, "They're probably going to cut off my brother's arm tomorrow." The group stared at Donald, and one member asked, "What did you say?" He repeated his statement, this time using his hand to indicate precisely where his step brother's arm would be cut. Note the arm length for every one of the family members in Donald's drawing. Could he be telling the viewer that "arms" were very much on his mind?

It was only after the group had explored "sibling concerns" that they were able to focus on Donald's brother's situation--how awful it would be lose your arm. Is he right-handed or left-handed? Which arm did you say it was? How will he eat? Brush his teeth? Write his homework for school? When one of the children said, "I'm glad its not me," all of the rest, including Donald nodded in agreement. The group reflected on the many amazing accomplishments of people with disabilities. They decided that at first it would be difficult for Darryl, but with Donald and his parents helping him, before long "things would be okay."

Case study 4: The Porter Family Just 3 years apart and both females, the Porter sisters seem to have a very warm and close relationship. Tracy, the oldest, was diagnosed with cancer of the colon 3 years ago. Now 14 years old, she is treated at a research hospital in another state, but receives routine follow-up care and lab work at the local clinic. There is some indication that the cancer has metastisized to a kidney. Although she feels and appears healthy, a spring visit to the research center would

answer the question. Should the answer be yes, Tracy will be scheduled for immediate surgery.

Usually the family goes together for Tracy's out of state appointments. Where past appointments have been over school vacations, this visit is scheduled while school is still in session. Uppermost in 11-year-old Carrie's mind is the fact that this time her parents planned to leave her home with her grandmother. Once before she had been left behind. "It was miserable," she said. "I didn't know what was going on. Even though my parents told me on the phone how Tracy was doing, I couldn't see for myself. And because I was here instead of there, how could I help her?" She was asked if she had discussed this with her family. "Well, sort of," she said. "They say that I shouldn't miss school." Although they knew she wanted to go, she really hadn't explained her feelings. The investigator, in explaining sibling day activities to Mr. and Mrs. Porter, described briefly some of concerns siblings typically have. Like most parents of children with cancer, they really had not had the opportunity to give the matter much thought.

Carrie's family drawing was scored only 1 point, a very adaptive drawing. This was given in the subscale "Emotional tone" for the clouds in the sky. In describing the drawing she said that her family is playing basketball together. (See Appendix C for scoring details.)

Insert Figure 4 about here

It is a real joy to observe the interaction between members of the Porter family. They communicate openly and apparently without difficulty. Their communication style had been established well before Tracy's diagnosis, and it seemed very natural to Mrs.

Porter that their style remain the same. "How could any of us deal with this if we didn't talk about it?" she asked.

This provided a perfect opening for Carrie to discuss the spring trip to the research center. She explained to her parents how terrible it was not knowing what was happening to her sister and not being available to offer comfort and support. Her mother mentioned that she would miss school. Carrie said she could get her assignments ahead of time, just as Tracy planned to do. "We'll think about it," said Mrs. Porter.

A week later Carrie ran into the clinic shouting, "I'm going to go with them!" Later Mrs. Porter explained that they started thinking about just how close the girls are and that maybe some things were more important than missing school. They are somewhat concerned about what would happen if they have to stay for an extended period of time or if things don't go well for Tracy. "We'll deal with it if and when it happens," said Mrs. Porter confidently. Undoubtedly, they will.

Case study 5: The Sellars Family. Mr. and Mrs. Sellars have three children: 5-year-old Laura, 3-year-old Bobby, Jr., and 2-year-old Crystal. They have been married for 4 years. Information regarding Laura's paternity is unknown to the investigator. Mrs. Sellars is employed as a waitress; her husband attends a local vocational school. Both parents have served terms in jail for drug related crimes. Laura was diagnosed with acute lymphocytic leukemia more than two years ago. Although her spirits seem high, Laura's puffy face and lab studies are indicators that her physical condition is poor.

Because her brother Bobby is only 3 years old, his drawing could not be scored using Spinetta et al's KFD-R. He did, however, place himself on the back of his family drawing although there was ample room on the front. This is sometimes an indicator that a child does not want to be a part of the family. At 5 years of age, Laura was also too young for a KFD-R score. However, scanning a KFD with certain questions in mind can often help nurses and other professionals understand what children are saying about

their families. (See Appendix B). For instance, 5-year-old Laura's KFD shows indicators of sexual abuse (See Figure 5).

Insert Figure 5 about here

Laura chose black and red to depict her family. Black and red or black and yellow are color combinations frequently used by sexually abused children. She pointed out the glass "crashing" in the top portion of the picture, another indicator. The children are together, "dancing." The monster in the lower left hand corner is stealing their food. The monster in the lower right hand corner is Freddie from the movie, "Nightmare on Elm Street." He is scratching on the window. Laura does not show her parents, or does she?

Nothing in her appearance or behavior during the limited time she spends at the clinic had given a clue about the abuse. She seemed a happy, polite, and well adjusted youngster. The family was referred to the clinic staff for follow-up. After 6 months of counselling, the suspicion of sexual abuse was confirmed.

Discussion

Siblings' drawings and follow-up discussions disclose not only the concerns about cancer, but also concerns about some of the changes common in families today. Many nondisease related stressors are a result of these changes or trends in our modern world, such as parental divorce and remarriage, geographic mobility, maternal employment and alternative sources of child care, competitive pressures, and various forms of parental insufficiency. Because brothers and sisters frequently rely on each other for support, when one member of the typical two child family has cancer, the

healthy sibling may be left with insufficient resources to cope, an important factor in determining the sibling's ability to adapt to stress (McCubbin & Patterson, 1983).

Some of these nondisease related stressors seemed evident in the many of the drawings in this study. For example, other children from single-parent families drew pictures similar to Scott's, with barriers between family members. Drawings of younger children from single-parent or divorced parents indicated confusion about defining their family. One child, in her first drawing, included her mother, but after a weekend visit with father, the drawing of her family included her father and his girlfriend. Often assorted relatives, friends, and strangers are included as "family" in one drawing, and absent in the next. In only one case did a child include her divorced parents together in the same drawing. Additionally, on interview and in the drawings, mothers in these families frequently appeared exhausted and unavailable to their children. Although the sample size of this study is too small to generalize, it was noted that mothers were typically not depicted as unvailable in drawings of families where two parents--whether step or natural--were in the home. Drawings from some of the children in the study may reflect reports that siblings of children with cancer living in a single parent family with little money and limited family and/or friends for support are particularly at risk (Laker,1988).

Research indicates that siblings in larger families tend to cope more effectively than those from smaller families (Powell & Ogle, 1985; Siemon, 1985). With, once again, a reminder that the sample size is too small draw conclusions, scores of drawings produced by children from the two largest (four children) families in the study were in the same range as those produced by children from smaller families, leaving this variable unsupported.

High access siblings--those similar in age and sex--are thought to develop a stronger emotional bond than low access siblings who are separated by more than eight

or ten years (Bank & Kahn, 1982). Drawings by the Porter sisters seemed to reflect an intense emotional bond, information that was verified by discussion and observation. Drawings from other high access siblings in the study, such as Scott and Timmy, could also indicate a strong and influential sibling relationship. Scott's stress could, in part, be a result of the fact that he could no longer rely on Timmy to share the stress common in many families today.

If the trend to have only two children spaced two to three years apart continues, we may soon be dealing almost exclusively with a population of siblings defined as high-access. Nurses and other health professionals need to consider the bidirectionality of the sibling relationship when exploring the benefits of interventions with siblings. Otherwise we may be missing opportunities to guide and encourage positive relationships among these siblings who, being the only two children in a family and close together in age, have a great deal of influence on each other. The potential exists for siblings to be a source of strength and comfort for each other. Health professionals may somehow be able to take advantage of this bond, use it in a positive way.

In closing, a plea is issued for health professionals including pediatric nurses to learn more about the language of art. Even in the small sample of this study, children chose drawing to communicate significant information that had been left unspoken. To accurately interpret drawings, certain cautions are in order. First, the professional needs a basic knowledge of the developmental stages of children's drawing. It is important to remember that children draw differently as they develop. What may be an maladaptive drawing for a 10-year-old might be perfectly appropriate for a child of 5. Second, clear, specific guidelines need to be established prior to the evaluation of any drawings. Other methods are available for interpreting the KFD. A grid may be used to help focus attention to particular areas. O'Brien and Patton (1974) use computers to score KFDs and establish criteria for interpreting KFD variables. Third, children's drawings should

always be assessed over time, since little replicability is seen in only one or two drawing from any child. Fourth, with any drawing, resist the urge to overinterpret. Children should be asked to validate what the interpreter thinks the picture represents, or at least be asked to discuss the picture beyond just drawing it (Lynn, 1987).

As we learn more about the effects of childhood cancer on healthy siblings, we are reminded that, just as with the child with cancer, a comprehensive approach to sibling intervention requires psychosocial assessment of nondiesease as well as disease related stressors. Siblings often reveal new and significant information that may be omitted by or unknown to other family members (Benoliel, 1970). Through the use of projective drawings and other valuable assessment and communication tools, siblings can make a considerable contribution to understanding the strengths and needs of the entire family. Families coping with health crises comprise a population at risk (Leavitt, 1984). While it is a population that is vulnerable to deterioration in mental health and family functioning, it is also accessible to supportive intervention. Through supportive interventions, nurses can provide families the opportunity to increase adaptive capacity and mental health as a family.

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Figure Caption

Figure 1. This drawing was done by 7-year-old Scott.

Figure Caption

Figure 2. Six-year-old Sally drew her family "playing in the backyard in the clubhouse Daddy built."

Figure Caption

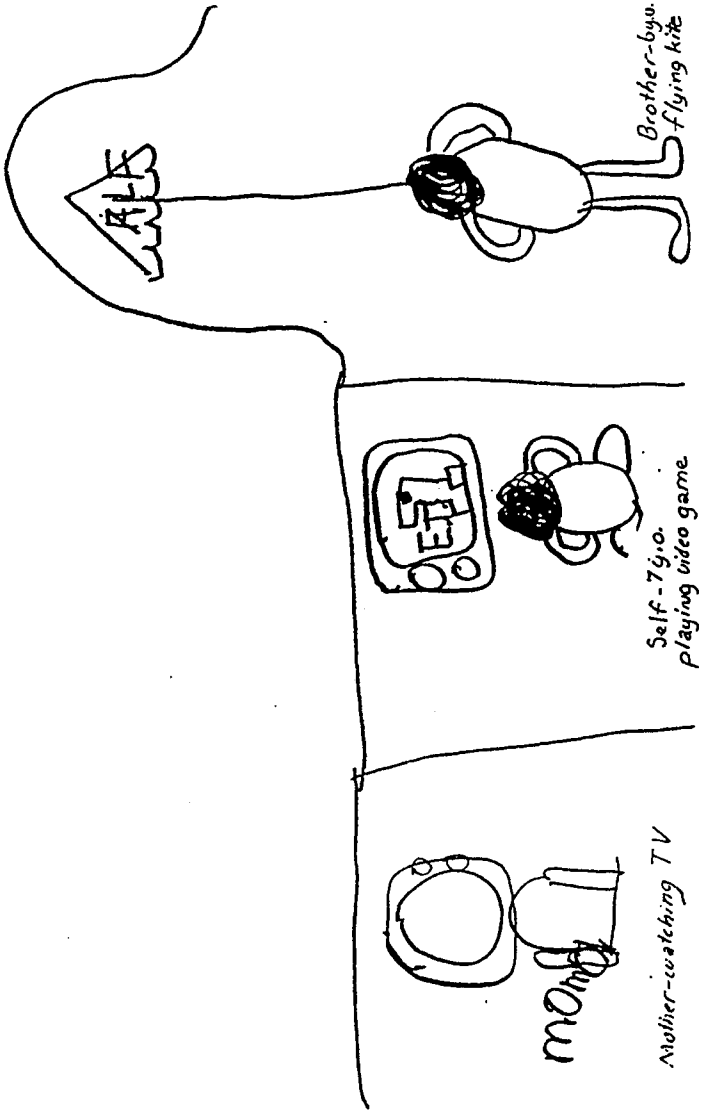
Figure 3. Nine-year-old Donald produced this drawing of his family.

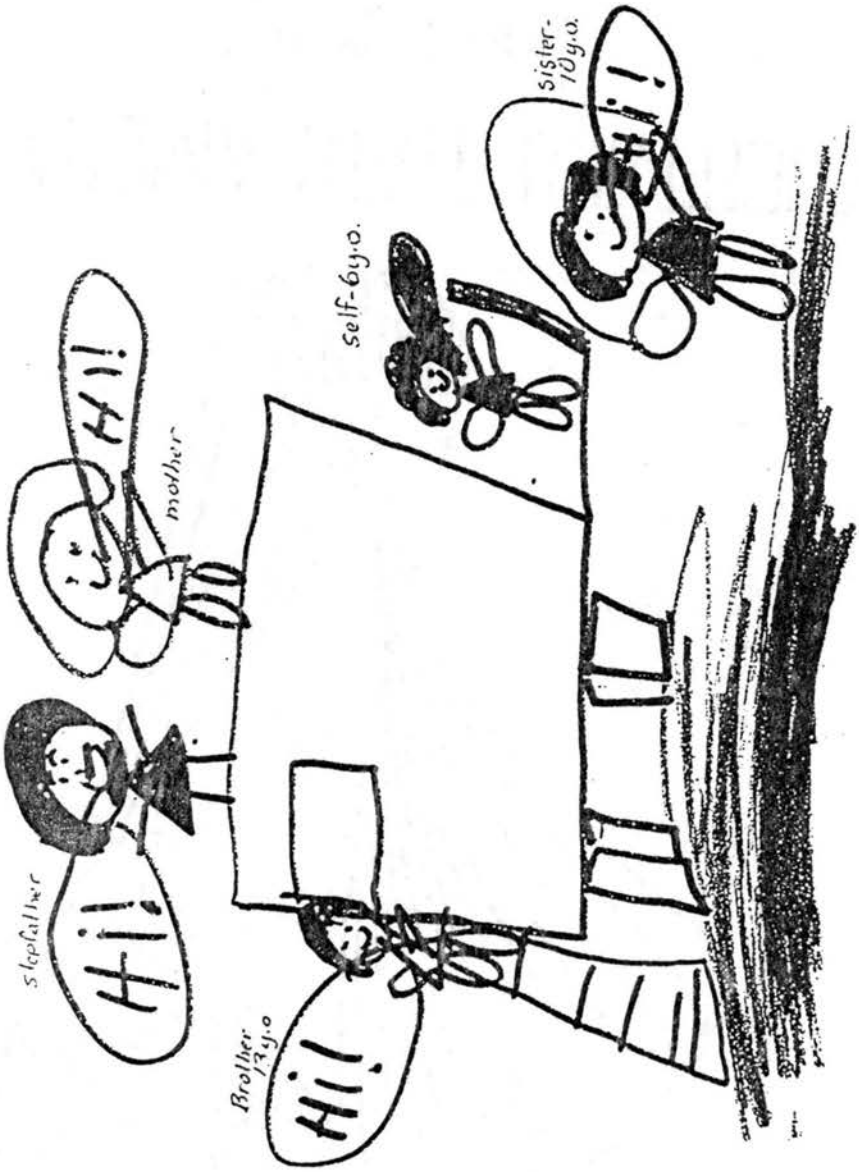
Figure Caption

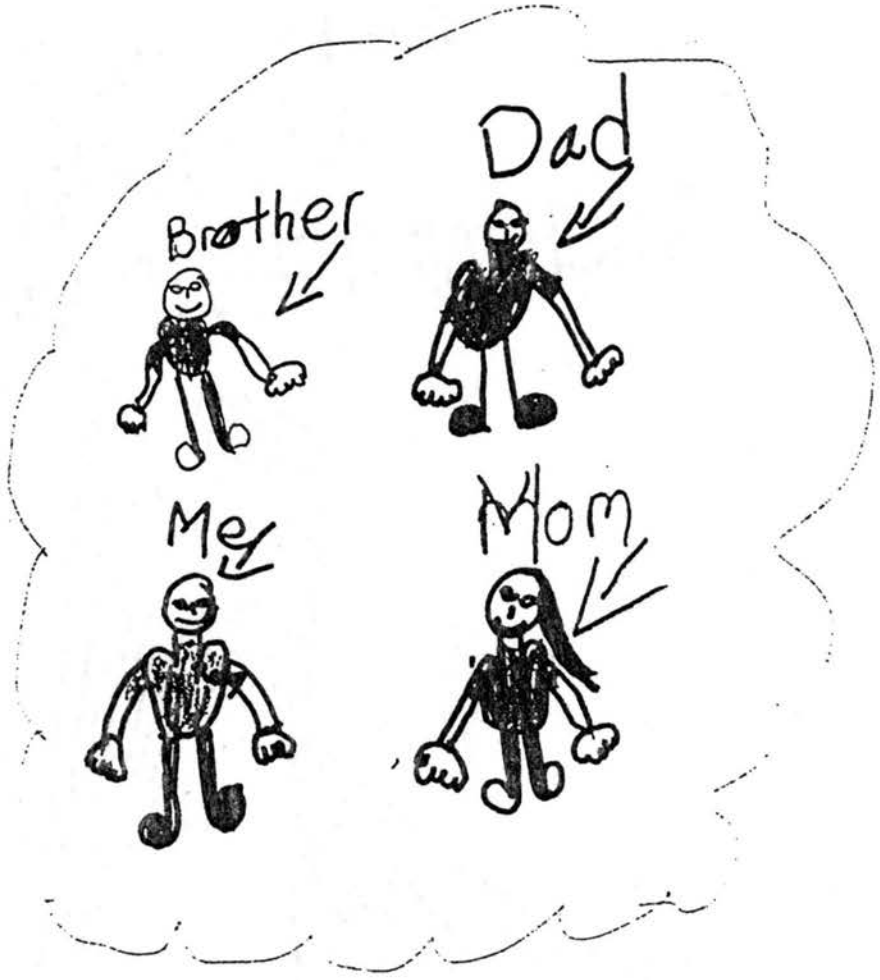
Figure 4. Eleven-year-old Carrie produced this drawing of her family playing basketball.

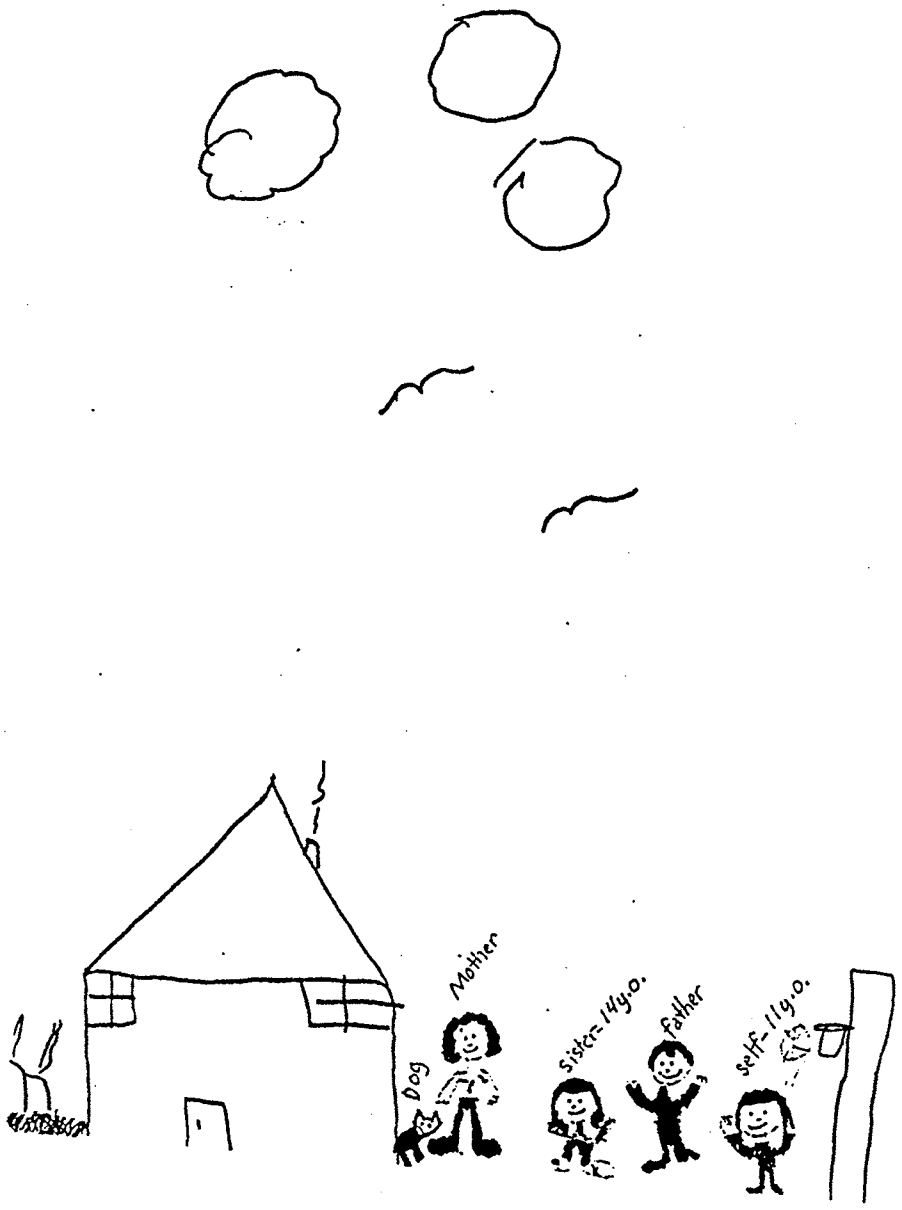
Figure Caption

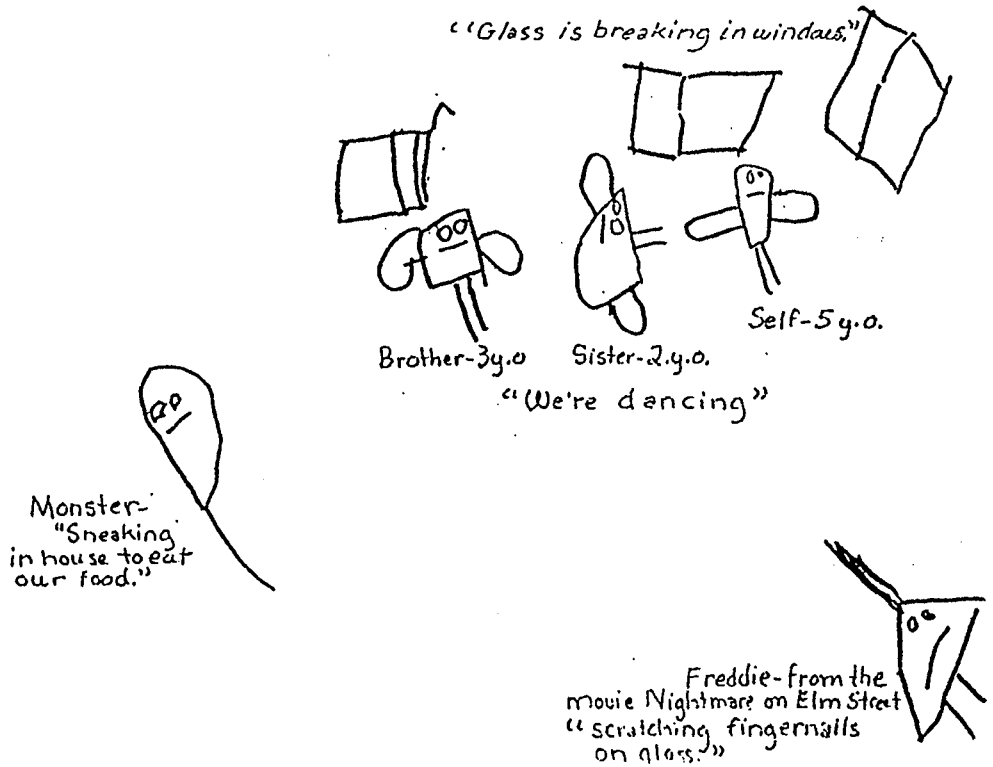
Figure 5. Five-year-old Laura produced this drawing of her family.


Brother-6yo.
flying kite
Self-7y.o.
playing video game
Mother-watching TV


Hi!
stepfather
Hi!
mother
Hi!
brother 13y.o
self-6y.o.
Hi!
sister-10y.o.


Brother
Dad
Me
Mom


Mother
Dog
sister-14y.o.
father
self-11y.o.


"Glass is breaking in windaus."
Brother-3y.o
Sister-2.y.o.
Self-5 y.o.
"We're dancing"
Monster-
"Sneaking
in house to eat
our food."
Freddie-from the
movie Nightmare on Elm Street
"scratching fingernails
on glass."

APPENDIXES

APPENDIX A

LITERATURE REVIEW

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LITERATURE REVIEW

Illness as a Stressor in the Family System

"Cancer: a malignant growth of tissue, usually ulcerating, tending to spread and associated with general ill health and progressive emaciation; a malignant evil that corrodes slowly and fatally." (Webster, 1959, p. 120). An old definition, yet one that even thirty years later continues to serve as the basis for ones initial emotional response to the word "cancer." Is it any wonder that news of such a disease in a family member would be sufficient cause for crisis in the family system?

Advances in treatment have resulted in dramatic improvements in life expectancy for children diagnosed with cancer. The cure rate for children who develop acute lymphocytic leukemia, the most common form of childhood cancer, has increased to 68%. The average survival rate twenty years ago was three to four months. Hodgkin's disease, almost always fatal in 1960, now has an 88% cure rate (American Cancer Society, personal communication, October 5, 1988).

The enormous improvement in cure rate of childhood cancer has shifted its classification from a "fatal disease" to "chronic, life threatening disease" (Van Eys, 1985). Although the outlook for today's child with cancer is considerably brighter than in the past, these children experience repeated hospitalizations and outpatient visits, months of chemotherapy, painful procedures, changes in appearance, lack of energy, and frequent absences from school. The demands of the disease, as well as the prognosis, are unpredictable elements to be dealt with on a daily basis.

Long recognized as a stressor, chronic or life threatening illness affects all members within the family system (Hill, 1949). When the family member is a child, the fact seems even more tragic, disrupting the natural order of life where the old suffer and die and the young carry on the work of the living. The impact of the diagnosis of cancer in childhood can be catastrophic to the family (Schlorlemer, 1988). Not only the patient, but the entire family experiences the crisis, long-term impact, and contingencies of cancer.

The Role of the Family

From the very beginning the family assumes a crucial role for the patient. Families serve as the first line of support, nurturance and interpretation of the cancer diagnosis for the patient. Therefore, the family becomes the buffer zone or context from which the patient attempts to derive personal meaning, purpose and self-worth (Lewis, 1986). Additionally, it is now a well established fact that families maintain the primary responsibility for the care of chronically ill or disabled family members (Montgomery, 1985). Typically, the family system helps to decrease stress for its members. In the case of chronic illness, however, stress is prolonged. The family finds it difficult to be a buffer for its members, and reorganization of the system needs to occur (Siemon, 1985).

Matters are further complicated by changes in today's families. Rather than the external supports that it once had, families today tend to operate at a high level of emotional intensity and maintain a heavy investment in its internal relationships (Leavitt, 1984). A major function of the family is to esteem the unique worth of the individual (Pratt, 1976). Other institutions have come to relate to the individual on an impersonal and manipulative basis. The family provides relief and also serves a mediating function on behalf of its members.

Response of the Family System

Members of the family are directly affected by the demands and stresses imposed on them as a result of the illness and its contingencies. Because of the interdependent nature of the family systems, cancer causes repeated "ripple effects" in the family (Lewis, 1986).

Initial impact of the disease. Initially, the impact of the disease and its treatment on the family is characterized by disorganization of the family structure. A knowledge of general systems theory is helpful in understanding what occurs. General systems theory views the child and family as a subsystem of the cultural or suprasystem. The child, as a subsystem of the family, interacts with the immediate family system and the suprasystem. The stress of the diagnosis will affect the child's system and suprasystem as well as the child him or herself (Hall, Hardin, & Conatser, 1982).

When such an event occurs within a family system, by its very nature of being a system, no part of that system escapes untouched. The classic study (Binger, Albin, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969) of the emotional impact of childhood leukemia on patients and their families presents a variety of responses from families. In the sixteen families studied, members initial feelings ranged from a loss of control to outward calm and resignation. After the first days or weeks, symptoms and feelings of physical distress, depression, inability to function, anger, hostility and self-blame, plus anticipatory grief appeared. These feelings gradually subsided and were replaced by acceptance. Persistent overt denial of the diagnosis or "shopping around" for doctors, different treatment, and so forth, were not found with these subjects. In 50 percent of the families, at least one member reacted so strongly to the crisis as to need psychiatric help.

Factors Influencing Family Adaptation

How the chronic condition effects the family, as opposed to the individual, is not well understood (Stuifbergen, 1987). In a critical analysis of the research literature on

the impact of cancer on families of adult patients, Lewis (1986) identified eleven separate areas of concern, most of which are relevant for childhood cancer: emotional strain, physical demands, uncertainty, fear of the patient dying, altered roles and lifestyles, finances, ways to comfort the patient, perceived inadequacy of services, existential concerns, sexuality, and non-convergent needs among household members.

An important consideration is the fact that the family system is not static. Developmentally, the family is changing constantly with the maturation of its members. Duvall (1977) describes nine stages of family development: beginning, expecting, childbearing, preschool, schoolage, teenage, launching center, middle years, and aging. Successful or unsuccessful completion of each stage contributes or interferes with healthy family functioning (Futcher, 1988). The family remains functional when modifications required to maintain balance are easily accomplished. Abrupt or unexpected family changes, however, such as hospitalization of a child, will result in role changes for everyone, often precipitating a family crisis.

> Commonly the mother will remain at the bedside, abdicating her maternal role at home to others. Temporarily, each member tries out new behaviors seeking a satisfactory fit with the new behaviors of all the other members. Each member also tries to cope with the loss of the well child and the unavailable mother. In the process, some needs of members may be unmet. Feelings of dissatisfaction, anxiety, frustration, and grief over the lost family equilibrium prevail (Burns, 1985, p. 13).

Chesler & Barbarin (1987) note that families residing more than 25 miles from the hospital report significantly greater stress in coping ability than those living closer to the hospital. Because the families did not differ with regard to other sources of social stress, the investigators conclude that the problems of travel obviously exact a special kind of personal wear and tear (Chelsler & Barbarin, 1987):

> In addition to the problems of travel time and energy, parents who travel further to this major treatment center might have children with more serious or complex illnesses or illness reactions, or illnesses requiring the availability of highly specialized personnel and facilities. Indeed, parents traveling further distances also report significantly greater medical stress--concern about a relapse and about fear of their child's death--than parents who live closer to the hospital (p. 59.).

Socioeconomic status. Families with lower incomes report more stress from personal concerns about their coping abilities and from stresses located outside the immediate family than do families with higher incomes. However, neither education nor income distinguish parents' reports of stress from their most intimate social relations, those from within the nuclear family (Chesler & Barbarin, 1987). To explain variation in income as a factor in coping with stress, the investigators suggest that those with lower incomes may have fewer ways of buffering themselves:

> An example of a buffering resource is a bank account. The financial impact of unemployment on a family with a low bank account is likely to be great. A family with a substantial bank account has a greater buffer between itself and deprivation. The same analogy may fit our emotional bank account. Poorer people may have smaller emotional and social bank accounts than wealthier people (Chesler & Barbarin, 1987, p. 61).

The medical expenses incurred with a serious illness such as cancer can be significant. But nonmedical costs associated with childhood cancer are also a consideration--one which higher income families are better prepared to meet:

> More affluent families also are better able to absorb or avoid the financial stresses associated with nonmedical costs of hospital parking, motels when the child is an inpatient, meals in the hospital cafeteria, unpaid

> leave from work, relaxing vacations, sitters for children at home, and so on. Thus, wealthier people may be better able to reduce the emotional and instrumental stresses that disrupt their personal lives (Chesler & Barbarin, 1987, p. 61).

Individual differences in response. Every member of the family may react differently. Koch (1985) studied 32 families having a child with recently-diagnosed cancer and identified changes in affect, symptoms of anxiety, symptoms of depression, responsibilities and restrictions on activities, and conflict at home and outside the family. The family system may become quite dysfunctional.

The manner in which a family responds to the diagnosis of childhood cancer is determined in part by each individual's perception of the disease and its treatment. This perception is often affected by faulty notions in the existential environment, such as:1) Only the very sick are hospitalized; 2) Only elderly people are sick; 3) With the increase in technology, surely there is a cure for everything; 4) Children should not suffer; 5) Being born in America guarantees a happy, healthy life; 6) Most, if not all, malignancies are fatal; 7) Diseases are punishment for previous sins or shortcomings (Hall et al, 1982). Other factors that influence a family member's response are individual personality structure, past experience, current crises, and the particular meaning or special circumstances associated with the loss threatening him. Beliefs about life, death and religion, response to previous crises, and current burdens and sources of support are also good predictors (Binger et al, 1965).

Communication style. Communication style may also affect the family's ability to cope with stress and solve everyday problems. Spinetta, Swarner, and Sheposh (1981) found a positive relationship between a family's favorable long-term adjustment to childhood cancer and its use of an open communication strategy. Chesler & Barbarin (1987) suggest what occurs:

> Open communication promotes joint problem solving or coordination of tasks, so that the activities of individual family members complement one another rather than overlap and duplicate. Moreover, when parents talk openly about their feelings, ill children and their siblings are also likely to join these conversations and, in turn, to promote open communication as a coping strategy for the entire family (p. 122).

Adaptation--Functional or Disfunctional?

While the initial crisis of learning of the child's cancer is usually resolved--whether functionally or disfunctionally--within six to eight weeks from diagnosis, family adaption to change in life style takes longer. Hall et al (1982) report that the child and family require approximately nine months to adapt to the change in life style that the diagnosis of cancer may institute. A new equilibrium will eventually be reached. If dysfunctional patterns develop they may or may not be permanent (Hoopes & Harper, 1987). Crisis can provide the opportunity for growth to occur through the learning and implementation of new coping strategies. Risk is also involved if the new coping strategies are weak or function for only the more powerful members (Burns, 1985).

Specific features of illness, family coping patterns, family communication, the stage of the family life cycle, or the social support available to the family and the ill member appear to be a few of the most critical elements that may determine whether the stress of the illness results in increased cohesiveness within the family, or a dissolution of the family unit (Stuifbergen, 1987). The effects of the crisis of the illness and subsequent reorganization of the family may be more disruptive functionally and emotionally to the well family members than to the patient (Stuifbergen, 1987; Spinetta, 1981). The true difficulty occurs when these effects are left uninterrupted and unmanaged, possibly causing long-term disruption not only to the child, but to the entire family.

A Population at Risk

The emotional strain for all family members is significant. While children with cancer can now expect to live free of disease or in remission for several years, families must learn to integrate the illness and treatment regimen into their daily routines, attempting to return their lives to some degree of normalcy (Kramer, 1984). And, while for any type of childhood cancer there is treatment available, whether or not the treatment will provide a cure is another matter (Hall et al, 1982). The uncertainty can prove unsettling for everyone.

Illness in a family member can easily overwhelm a family's coping ability with these intense interdependencies and unrealistic expectations of themselves. Because there is little margin for shock absorption, the family is highly vulnerable in times of crisis and change. Such families are at risk due to the very same intensity of emotional gratification that is the sustenance of family life in today's society. Disruption in family role relationships caused by illness threatens the family's satisfying continuity, the mental health of its members, and at times, even its very existence. Families coping with health crises comprise a population at risk. It is a population that is both vulnerable to deterioration in mental health and family functioning and accessible to supportive interventions and the opportunity to increase adaptive capacity and mental health as a family (Leavitt, 1984).

The Sibling Relationship

Most children have at least one sibling, with only about 10 percent having no siblings at all. In the United States and Europe, 80 percent of children grow up with siblings. While acknowledging that siblings comprise a subsytem, family experts, with their sensitivity to group dynamics and reciprocal social influences in the family, have focused very little on the interaction between these members of the same generation (Bank and Kahn, 1975; Bank & Kahn, 1982). Often ignored is the concept of an

individual in the process of becoming or a description of what brothers and sisters mean to, or think about, each other. Little attention has been given to the emotions and feelings within the sibling subgroup itself.

Cross-cultural Differences

In the United States and Western Europe, there is a general under-emphasis of sibling status because these cultures typically emphasize the romantic aspect of family life, namely husband-wife relationships and the product of that union, the children (Bank & Kahn, 1975). But in less technologically advanced societies, such as African cultures south of the Sahara, paths between generations are de-emphasized, fraternal solidarity is more important than romantic love, and loyalty and the control of rivalry among brothers are the cornerstones of family stability. Weisner (1982) presents a cross-cultural view that suggests a number of aspects seldom considered:

> Sibling conjointly perform important, responsible domestic tasks and chores essential to the subsistence and survival of the family; they are involved in cooperative child rearing; in defense, warfare, and protection; in arranging marriages and providing marriage payments. Siblings in most of the world strongly influence much of the life course of their brothers and sisters by what they do. They share life crisis and rite of passage ceremonies essential to their cultural and social identity; they take on ritual and ceremonial responsibilities for each other essential to community spiritual ideals. The sibling group in most societies around the world participates jointly throughout the life span in activities essential to survival, reproduction, and the transmission of cultural and social values (p. 305).

Roberts (1982) reminds us that our Western culture marks important changes between parents and children, such as the rituals of infant baptism, circumcision,

confirmation, bar mitzvah, and graduation. The bonds between husband and wife are celebrated by engagements and weddings, legalized by marriage and divorce, and validated by the development of marriage and divorce therapy. But there are no legal means to make or break the sibling bond nor rituals of church or synagogue to celebrate them.

American Culture Today and Its Influence on the Sibling Relationship

With the trend in America toward greater equality between siblings resulting from the reduction in the custom of primogeniture and the increase in women's rights, there is a trend toward greater freedom and separateness. The loosening of obligatory ties has also led to sibling relationships sharing in the trend toward greater freedom of choice to be involved or not involved. However, other forces may be propelling sibling into greater contact and emotional interdependence than ever before. Certain changes in our modern world may be giving the sibling relationship greater rather than lesser relevance: shrinking family size, longer life spans, divorce and remarriage, geographic mobility, maternal employment and alternative sources of child care, competitive pressures, and stress and various forms of parental insufficiency (Bank & Kahn, 1982).

Decrease in family size. Since the turn of the century, family size has shrunk considerably. Today the average child has one sibling (David and Baldwin, 1979). The two-child family is considered the American ideal. The reason supporting the need for a sibling is the belief that children acquire desirable interpersonal characteristics as a consequence of sibling interaction (Falbo, 1982). In addition to creating the potential for interdependence and intensification of the relationship, having only one brother or sister gives one sibling an enormous power to have exclusive influence over another sibling (Bank & Kahn, 1982). The children are typically spaced about two to three years apart, further forcing the children into contact, dependence, and competition and heightening opportunities for mutual influence. It should be noted, however, that shrinking family

size has made the sibling sub-group and sub-groups within the sibling sub-group less visible (Bank & Kahn, 1982).

Increased life span. Improved nutrition and medical care have lengthened the life span of the average American well into the seventies and eighties. In the future, an increasing number of siblings will undoubtedly be more likely to share apartments (and nursing homes), ending their lives together rather than apart. Cicirelli (1977) reports growing evidence that siblings provide a highly supportive social network in old age when spouses die, and children have gone their separate ways.

More active sibling relationships. Many trends and changes result in a greater reliance of siblings on each other. Brothers and sisters may look to each other for emotional as well as practical support. Geographic mobility remains a trend in the United States. A new neighborhood, new friends, a new school, often leave a child with one constant person to turn to: a brother or sister. Siblings may be forced to rely on each other more intensely (Powell & Ogle, 1985).

With the rise in divorce rates of at least sevenfold since 1900, children are faced with the trauma of parental breakup and dislocation. While each child experiences the divorce individually, siblings often join forces to confront the trauma together. Because the majority of divorced persons remarry, the new family system must adjust to new members, relationships, loyalties, and so on. Here again, siblings often rely on each other for support (Bank & Kahn, 1982).

There is an increase in the number of working mothers, particularly those with preschool children. While much debate surrounds the issue of the negative impact of the dependence upon parental surrogates during these formative years (Etaugh, 1980), it does appear that young siblings today have large amounts of time when their relationship is not monitored by a personally committed adult. Often an older sibling is

required to baby-sit, resulting in children spending more and more time together unsupervised.

Many parents today are experiencing severe stress resulting in their being unavailable to their children for longer periods of time. Although the effects of deprivation of parental care on the individual child has been the subject of numerous clinical studies, rarely has the traumas' effects on the sibling relationship been noticed. It is felt, however, that the sibling relationship may be activated (Bank & Kahn, 1982).

Increased competition. As American society advances in the realm of technology, our culture becomes more exacting and competitive. Competitive pressure for success in the outside world is likely to increase among children in the same family (Bank & Kahn, 1982). Siblings will tend to use each other as yardsticks for comparison.

In summary, Bank & Kahn (1982) suggest that in the United States children today are growing up in a vastly more complex world than did their grandparents:

> --a world where opportunities for contact, constancy, and permanency are rare. Children are biologically propelled by these vital needs--what some psychologists call "object constancy"--to turn for satisfaction to any accessible person. In worried, mobile, small family, high-stress, fast-paced, parent-absent America, that person can be a brother or sister (p. 15).

Uniqueness of the Sibling Relationship.

Perhaps the most unique of all features of the sibling relationship is its duration (Cicirelli, 1982). Likely the longest relationship one will share with another human being, the sibling relationship lasts through a lifetime, often fifty to eighty years as compared with the child-parent relationship which is usually from thirty to fifty years in duration (Bank & Kahn, 1975). Additionally, siblings are together for long periods at a time. They may spend hours, days, weeks, or even years together. Contacts may range

from bathing, sleeping, playing, changing clothes, arguing, and so on (Bossard & Boll, 1960). There is a stark frankness in the sibling relationship:

> Siblings come to know each other by the book. They come to live largely with each other--to use the vernacular again--"with their hair down." Life among siblings is like living in the nude, psychologically speaking. Siblings serve as a constant crude awakening (p. 91).

The sibling relationship is also unique in that the children share a common genetic heritage, common cultural milieu, and common early experiences within the family. The relationship between siblings is highly egalitarian, with the siblings sharing approximately equal power in the relationship. Finally, the sibling role is an ascribed rather than an earned role, so that an individual remains a brother or a sister regardless of achievements or circumstances. The intimacy of the relationship is quickly restored even after long absences (Cicirelli, 1982).

Sibling Functions

While it is clear that parents supervise and monitor sibling relationships, there is a limit to the influence of parents over the sibling system. Siblings are more to each other than their parents wishes and expectations (Cicirelli, 1982; Bank & Kahn, 1975). They exert power, exchange services, and express feelings in a reciprocal way with one another that is often not revealed explicitly in the presence of parents. Four basic functions that siblings serve for one another relatively free of parental monitoring have been identified (Bank & Kahn, 1975).

Identification and differentiation. It has been hypothesized that that one's self-concept as a young child emerges from one's earliest intimate relationships. As a grown person, in intimate relations such as marriage, one repeats that pattern of involvement in a healthy or a disturbed way.

Object relations is a term that refers to psychological processes that all people use, early in life, to create internalized images of the self and other people. The dynamic relationship between these "object representations" creates the foundation for intimate relationships through one's life (Bank & Kahn, 1982):

> The development of identity, the deepening of the capacity to endure frustration and fluctuation in intimate relationships, the growth of the ability to love and empathize, to be faithful and trusting, all stem--in the object-relations view--from the quality and the durability of the people upon whom one depends, and from the way in which the child internalizes these experiences in the first years of life (p. 30).

While in the past it has been assumed that the parent was the most important person with whom the young child interacts, Bank and Kahn (1982), acknowledge that in today's world where the parents are often much less available that they might optimally be, a brother or a sister close at hand becomes a likely candidate to be that warm and reassuring important external object. Three major groups of the most common sibling relationships, some which are transitory, others endure for a lifetime are close identification, partial identification and distant identification. In close identification each person feels great similarity and little difference with a sibling, in partial identification, each person feels some similarity and some difference, while in distant identification, each feels great difference and little similarity with a sibling.

This process by which one child sees himself in the other, experiences life vicariously through the behavior of the other, and begins to expand on possibilities for himself through a sibling's experience is a powerful phenomenon--the "glue" of the sibling relationship (Bank and Kahn, 1975). Because siblings tend to spend more time alone together than alone with a parent, the possibilities for identification with brothers

and sisters are more abundant than the possibilities for parent-child identification, although the motivation for identification may be less.

Differentiation is another key process among siblings. Siblings can be touchstones for what the other would not like to be. Without adequate differentiation, a dangerous process of fusion can occur which blocks the growth of each child.

Mutual regulation. Because siblings serve as sounding boards for one another, they offer a safe forum for experimenting with new behavior where new roles are tried on, criticized, encouraged, or benevolently acknowledged before using either with parents or non-family peers. By providing an "observing ego" for one another, they can exert an effective and corrective impact upon, and for, each other. Because the sibling relationship is a relatively equal one, brothers and sisters usually proceed on the basis of fairness and honesty.

Direct services. Services range from tangible ones such as lending each other money, clothing, toys, sports equipment, teaching a skill, and so on, to help with childhood problems, support in dealing with parents or others outside the family, or an introduction to a new friendship group (Cicirelli, 1982; Bank & Kahn, 1975). In providing services for one another siblings may learn the fine art of negotiation and bargaining--and sometimes manipulation.

Dealing with parents: coalitions. The manner in which a child manages his relationship with his parent can benefit or harm another. Siblings often function in the balancing of power of the parents. Siblings can protect one another from parental-executive abuse of power. Bank and Kahn (1975) offer the example of an older sister suggesting that she and her brother go for a walk when their alcoholic father became abusive toward him.

Another important function is joining. Alliances develop between siblings. Hoopes and Harper (1987) define the process as follows:

> Attempts to deal with the issues of authority, power, and emotional support often lead to the formation of alliances among family members. An alliance is an implicit agreement between two or more people to give emotional support to each other or to secure greater power (p. 7).

Negotiating with parents is stronger with siblings acting together rather than singly. Additionally, if both siblings are misbehaving, neither sibling can be seen as the only offending party.

Because siblings often know much more about one another's behavior than either of the parents, tattling can be an important lever in the relationship between siblings. On the other hand there is often a conspiracy of silence among siblings, leaving the parents feeling isolated and excluded. As guardians of each others' private worlds, a willingness to make and maintain each other's privacy often serves as a powerful bond of loyalty among the children (Bank & Kahn, 1975). Siblings often serve a translating function between their world and that of the adults. Zuk, (1972) refers to a go-between process where siblings medicate between one another. They mediate the outside world for their parents and may mediate the parents' relationship. Additionally, siblings interpret the outside world for each other, as well as, as a group, performing genuine educative functions for the parents.

A somewhat related function is pioneering. In pioneering, one sibling initiates a process thereby giving permission to the others to follow accordingly. Patterns may include breaking explicit family rules, taking new developmental pathways such as leaving the family, or adopting different moral/political codes and lifestyles (Bank & Kahn, 1975; Cicirelli, 1982).

Sibling Access

Bank and Kahn (1982) posit that the emotional bond between brothers and sisters depends greatly on "access." Siblings who appear to have little emotional impact upon

one another are defined as "low access" siblings and have some of the following characteristics:

> They are often separated by more than eight or ten years, acting almost like members of different generations. They have shared little time, space, or personal history, partaking of different schools, friends, and parents (since people are different parents at different ages) in very different ways. They lack the sense of a shared history. They have not needed one another, nor have their parents needed for them to need each other (p. 10).

High access siblings, on the other hand, are generally similar in age and sex, as this circumstance promotes access to common life events. Therefore, the most extreme case of high access would be identical twins. This is not to say that bonds are nonexistent between siblings with large age spans, nor that there will always be a strong bond felt between siblings with only a year or two difference in age. However, high accessibility during the developmentally formative years is the almost routine accompaniment of an influential sibling relationship. In addition to similarities in age and sex, characteristics of high access siblings include the fact that they have often attended the same schools, played with the same friends, dated in the same crowd, been given a common bedroom, (even the same bed), worn each other's clothes, and so on.

Bank and Kahn (1982) further note that the earlier access begins, and the more prolonged it is, the more intense will be the relationship between siblings when it is stressed by the issues of separation, death, and social comparison in later life.

Sibling Reaction to Childhood Cancer

Sometimes termed "the forgotten ones," siblings are, by most recent accounts, the most left out and unattended to of all family members during the experience of serious childhood illness (Chesler & Barbarin, 1987). Family, friends--even

professionals--focus on the ill child and the parents. In the process, siblings are frequently overlooked (Laker, 1988). Research findings concur. In a 3 year study of siblings of children with cancer, Spinetta (1981) reports that the emotional needs of siblings are met at a level significantly less adequate than those of other family members. Siblings scored at significantly lower levels of overall adaptation on the criterion measures. They also scored at lower levels of adaptation in specific tasks and in response to individual tests. In response to the Kinetic Family Drawing Test used in Spinetta's study, siblings had the most persistent negative responses to each of the disease-related variables: disease stage, frequency of clinic visits, visibility of illness, and patient's level of pain or physical discomfort. In a more recent study of chronically ill children, healthy siblings were identified as the most unhappy members in one third of the families interviewed (Tritt & Esses, 1988).

Disease Dictates Changes in Relationships

Studies indicate that drastic changes occur in the healthy sibling's relationships with parents and the ill sibling. Some of these changes are a result of demands of the disease itself. The sick child becomes the focus of parental attention and concerns, resulting in a shift in family dynamics. Family organization and roles change. Ill family members do not complement the rest of the family as they use to: "An ill member is 'out of tune,' unable to contribute to the family in his/her usual way, or is making new demands on the family" (Siemon, 1985, p. 27).

Separation and disruption of family routine. Frequent family separation caused by repeated hospitalizations and trips to the medical center for treatment is one of the most disrupting and stressful consequences healthy siblings face. The well children find themselves pushed to the background, often staying at the homes of family and friends. Long distances and strict hospital rules may interfere with visitation. (Kramer & Moore, 1983). Demands of the disease and therapeutic regimen disrupt normal family routines

and may interfere with holiday celebrations, vacations, and social interactions. Healthy siblings may resent this intrusion in their lives which frequently demands self-sacrifice (Kramer & Moore, 1983). Parents may be unable to attend the siblings' school functions, ball games, or other activities (U.S. Department of Health and Human Services, 1986). Parents are often physically and emotionally unavailable for the healthy siblings (Kramer, 1981; Sourkes, 1980; Kramer & Moore, 1983). The family's financial resources as well as emotional resources may be directed toward the child with cancer. When this occurs, there is often not only in a decrease in normal family activities, but a decrease in personal items for the healthy sibling as well (Trahd, 1986).

Nature of the sibling subsystem. Many of the difficulties siblings encounter are a result of the nature of the sibling relationship itself. It is within the sibling subsystem that children learn to share, compete, and compromise with others close to them in status. Healthy siblings lose their equal relationship with the disabled brother or sister (Trahd, 1986):

> Healthy siblings yearn for someone with whom they can tell their secrets, play, and talk about their parents. Siblings feel this loss even more in a two-child family (p. 192).

Illness places constraints on siblings when love and competition have been part of their ongoing relationship. Because one member is ill, siblings are no longer able to compete, at least temporarily. Similarly, when love for one another can only be expressed by long distance phone calls or an occasional visit in a hospital room, it may not come as easily (Chesler & Barbarin, 1987).

Siblings are often treated differently than the ill child. The ill child receives preferential treatment, with parents tending to be lenient in discipline as well as overindulgent and overprotective (Kramer & Moore, 1983). This may lead to resentment and jealousy. Cairns, Clark, Smith, and Lansky (1979) report that siblings

of chronically ill children with cancer see their mothers as overprotective and overindulgent of the ill child. Reports from mothers do bear out the reality of some of these perceptions. Siblings may help draw their parents' attention to these overreactions. Sometimes siblings' perceptions are distorted due to their own sense of loss, jealously, and concern (Chesler & Barbarin, 1987). In interviews with 27 siblings of chronically ill children, 39 percent reported feeling jealous of the ill child (Tritt & Esses, 1988).

Identification, common to many sibling relationships, can also be a source of concern. Because siblings often identify with one another and link their fate with one another's experiences, the well siblings may feel responsible for the child's illness, thinking that perhaps the illness was caused by their rough play with their brother or sister. Furthermore, if one sibling gets ill, the other may expect to get ill as well. (Sourkes, 1980; Spinetta, 1981; Chesler & Barbarin, 1987). Sourkes (1986) notes that the fear of becoming ill with cancer runs high among a sibling group, with ample reason for this frightening identification:

> Siblings see many similarities between themselves and the patient. As children in the same family, past experiences that affected one child often affected another. Thus, siblings use projection to think that an illness that could befall one child could just as easily befall another, especially when the siblings cannot stipulate, either cognitively or emotionally, a cause for the illness. The apparent randomness of events lead the siblings to think, "Why not me, too?" (p. 20).

Peer relationships. Studies also report strains in relationships with peers (Iles, J. 1979; Kramer & Moore, 1983). In the beginning, not knowing what to say or fearing that cancer is contagious, friends may avoid the sibling. Out of fear or ignorance, siblings are sometimes intensively taunted about their brother or sister's condition. Insensitive comments such as "Your brother is going to die," are not uncommon

(Chesler & Barbarin, 1987). Teasing often occurs about the appearance of the child with cancer who may be bald from treatment or "puffy" from steroids. Healthy siblings often feel torn between hiding themselves from embarrassment and protecting their disabled sibling from ridicule (Trahd, 1986):

> Although they love their disabled brother or sister, healthy siblings have the desire for peer involvement. They often are forced to choose between loyalties in what amounts to a no-win situation. This confusion often causes healthy children to become angry at themselves, their brother or sister, and their friends (p. 192).

Perhaps the cruelest of blows occurs when parents of peers restrain their children from playing at a house where someone has cancer. Playmates may disappear for the healthy siblings as well as the child with cancer (Sourkes, 1986).

Sibling Response

Because of the paucity of information in the literature on how siblings normally respond to and interact with each other, ascribing meaning to the behavior of siblings of children with cancer is a major problem. A variety of research findings perhaps indicates that sibling response is a very personal and individualized response (Siemon, 1985):

> Like human beings in general, the sibling group is complex and cannot be easily categorized into a "recipe." Not only do sibling groups vary widely in their responses, each of the siblings in a family needs different help and support because of the complexities and uniqueness of their personalities (p. 27).

While many concerns of siblings are universal,the mode of expression may depend on children's cognition and emotional developmental stage (Sourkes, 1986):

> Some of their reactions that initially seem disruptive may, in fact, represent an adaptation to a unique life stress. The concerns raised by the siblings do not begin and end at specific points in the illness of the patient. Rather, in an ebb and flow fashion, they recede or resurge in importance at different times. In the same way that others acknowledge normal stages and reactions in the patients' adaptation, so they must see the siblings' experience in this perspective (p.19).

Feelings. Most siblings experience mixed and sometimes contradictory feelings. Parents note that siblings feel left out of new family developments and changing roles and may become deeply upset. These feelings are often expressed in ways that draw parents' attention and concern:

> In some families these concerns are quite minimal, as siblings move in to play major housekeeping and child-care roles, taking some of the pressure off parents. Typically, older sibling are especially helpful, whereas younger siblings are a major cause of worry (Chesler & Barbarin, 1987, p. 56).

Siblings' sense of guilt is multifaceted. Views on what caused the patient's illness may include either an implicit or explicit self reference (Sourkes, 1986):

> Beyond the issue of causation, siblings at times feel guilty that they escaped the disease. Acknowledging their relief at being healthy only triggers the guilt more intensely. These children often feel bad when the patient is unable to participate in a particular activity or event because of illness (p. 20).

Having a brother or sister with cancer labels their family as being different, causing the healthy siblings embarrassment and frustration over answering endless questions about the ill child's condition (Kramer & Moore, 1983).

> Rarely mentioned, but often lurking, is another source of sibling guilt: shame at having a child in the family who is ill, disfigured, or dying. The patient marks the family as "different." Siblings may attribute their shame either to themselves or to the patient; in both cases, the unacceptable feeling only increases the preexisting guilt (Sourkes, 1986, p. 21).

Resentment is common. Siblings often must sublimate their personal needs for those of the child with cancer (Trahd, 1986). Sourkes (1986) reports an additional source of resentment for older siblings: Themselves deprived of attention from parents, older siblings may resent stepping in as surrogate parents for the younger siblings. A painful issue is siblings' anger at the parents for not having been able to protect the child from the illness. Parents may be perceived as having played a role in the occurrence of illness (Sourkes, 1986):

> Young siblings may come to this conclusion through a magical juxtaposition of events. Older siblings may wonder why the parents didn't check the patient's symptoms earlier, echoing the parents' own self-questioning (p. 21).

Siblings may also experience an additional source of anger--anger from the ill child. The child with cancer, angry to be sick, resents the siblings for escaping the illness. The patient's anger, rarely mentioned in the literature, can be quite devastating to the healthy siblings (Sourkes, 1986). Often overlooked is the positive caring between siblings (Powell & Ogle, 1985; Sourkes, 1986). Given the problem-oriented perspective of the clinical literature, the lack of information of a positive nature is not surprising.

Behavior and adjustment difficulties. A healthy sibling's response to having a brother or sister with cancer is often reflected in behavior or adjustment problems. Siblings of children with special needs are more likely to experience adjustment or

behavior problems than are their peers where all children in the family are healthy (Gallo, 1988). Such problems are fairly common and can indicate that the sibling is having trouble dealing with the situation (U.S. Department of Health and Human Services, 1986).

Research indicates that siblings in families of children with cancer are under substantial stress which may result in escalated anxiety, and increased sense of isolation, and fears about their own health problems (Cairns et al, 1979). Problems noted may be minor or severe: enuresis, headaches, poor school performance, school phobia, depression, severe separation anxiety, and persistent abdominal pain (Binger et al, 1969). Sourkes (1986) reports that physical problems, sleep problems, and proneness to injury are common to siblings of children with cancer, possibly as a means of getting parental attention. There is also evidence that some children will overachieve in school, perhaps as a method of capturing attention (Sourkes, 1986). Or maybe, --much like the father who immerses himself in his job--siblings, too, have discovered a means of coping.

Factors influencing sibling reaction

Age, birth order, and gender. Age, birth order, and gender may influence the sibling's reaction. A sibling just younger than the child with cancer is often at greatest risk because of the young child's need for attention. The infant sibling is at highest risk because the mother, preoccupied with the sick, is unable to respond to the infant's cues (Lindsay & MacCarthy, 1974). The older sibling often feels very protective of the ill child. This sibling, particularly if female, is likely to be involved in the ill child's care (Powell & Ogle, 1985).

Closeness in age and birth order may be important risk factors. In 1982 Breslau compared 237 siblings of disabled children with 248 siblings from a random sampling of families. Breslau found that younger males who were close in age to the disabled child had a higher incidence of psychological impairment than older male siblings, mirroring

Gath's findings from 1972. The opposite results were noted for female siblings (Breslau, 1982). Earlier studies (Tew & Laurence, 1973; Lavigne & Ryan, 1979) report opposite findings, yet confirm Breslau's research that healthy sibling have higher stress levels and are at risk of experiencing psychological difficulties. In general, sibling adjustment is better when the ill child is a female or the opposite gender of the sibling with the exception of the older female (Siemon, 1985).

Preschoolers are concerned about time and attention devoted by family members and professionals to the child with cancer, parental distress and preoccupation with the child, etiology of the condition, and worry that they may be affected as well. The preschooler may reflect these concerns through acting out behaviors, such as dramatic play with injury or death themes. Without realistic information, they use magical thinking to supply their own explanations (Sourkes, 1986; Rothery, 1987). Some preschoolers become irritable and withdrawn (Powell & Ogle, 1985).

School-aged siblings are concerned with changing roles within the family, additional responsibilities, how to tell peers, how to talk to parents about their role, and uncertainty about the exact nature of their brother or sister's condition (Rothery, 1987). They may act out socially, particularly at school Female school-aged siblings tend to have more problems than male school-aged siblings. In adolescence it reverses and seems to be easiest on females, except for the daughter who is placed in a caretaker role (Powell & Ogle, 1985).

The adolescent sibling worries about the future. To adequately cope with the situation, teenage siblings need more sophisticated information about the child's condition, its cause, treatment and prognosis (Rothery, 1987).

Nature of the cancer and treatment course. Research findings differ concerning the child's degree of disability as a predictor of adjustment problems in siblings. Some studies report more problems when the disability is greater; others, the opposite

(McKeever, 1983). Visibility of the condition may be a factor (Lavigne & Ryan, 1979). This factor plays an important role after diagnosis:

> An illness that leads to a dramatic physical change such as an amputation provides a visible focus for explanation. Yet, siblings may grapple with whether the patient is still the same person, despite the altered appearance. Young siblings may be puzzled by the invisibility of a disease like leukemia and supply their own real and imagined symptoms. Loss of hair and weight become visual cues in most illnesses; however, the effect is less enduring than that of an amputation (Sourkes, 1986, p. 20).

Brother or sister's loss of a limb or visible side effects from chemotherapy are sometimes a source of embarrassment for siblings among peers. On the other hand, adjustment is often facilitated by actually being able to see that something is wrong or different about the child with cancer. Siblings typically have more adjustment difficulties when the child's condition is ambiguous or undefined (McHale, Simeonsson, & Sloan, 1984), and when the prognosis for the child's recovery is not good (Laker, 1988).

Spinetta (1981) found the patient's level of pain and physical discomfort critical variables in sibling adaptation. While for the patients and parents the worst adjustment occurred at mild pain levels, siblings indicated more maladjustment at the level of severe pain and physical discomfort of the patient. Disease -related variables such as disease stage, frequency of clinic visits, visibility of illness, and physical discomfort of the patient have an effect on the healthy siblings. Although the patient moves through and adapts to changes in each of the four disease-related variables at a relatively adequate level, the sibling does not: "The sibling is affected more seriously by changes caused by the disease than are any of the other family members (Spinetta, 1981, p. 97). Even

remissions are difficult . The healthy siblings see that their parents are no longer spending time in the hospital or clinic with the ill child and feel that it's finally their turn for attention Exhausted physically and emotionally, parents often use the time to relax (Spinetta, 1981). The sibling's unfulfilled expectations lead to disappointment and distress.

Sibling understanding of cancer. A healthy sibling's response to his brother or sister's cancer is largely a result of his understanding of the disease. Understanding is influenced primarily by the sibling's stage of development. Children often hold two views of the cause of the disease: one from the medical information they may have heard from parents or a doctor, and a "private version" based on their cognitive level of understanding (Sourkes, 1986). Acting on this level of understanding, young children often view the illness as a punishment, while those ages 7-11 years view disease as contagion. Children 12 years and older are able to use logic and develop a more accurate understanding. Siblings, particularly young ones, often believe that they caused their brother or sister's cancer and feel guilty (Spinetta, 1981; Sourkes, 1986).

Craft, Wyatt, and Sandell (1985) found that the type of explanation for cancer was a determinant of sibling reaction:

> It was surprising that siblings who received limited explanations reported more changes than those given no explanations. It is possible that a vague explanation creates anxiety. Importantly, the most desirable outcome resulted from open explanations (p. 377).

While reports indicate that siblings are less informed than any other family member (Spinetta, 1981; Sourkes, 1986), neighbors look to siblings for information about the child with cancer. Lack of information and understanding about the disease, perhaps coupled with the parent or child's wish to keep the condition a secret, all serve to make the role of family informant a very uncomfortable one for siblings.

Additional factors. Other factors may influence sibling response. Siblings in larger families tend to cope more effectively than those from smaller families (Powell & Ogle, 1985; Siemon, 1985). Particularly at risk are siblings living in a single parent family with little money, and limited family and/or friends for support (Laker, 1988). Siblings from varying socioeconomic levels react in ways that are qualitatively different:

> Those in low SES families react to the burden of care as a function of financial drain. Those in high SES families respond to the stigma of a handicap or illness as a function of expectations of achievement that are unmet (Siemon, 1985, p. 28).

A dysfunctional parenting style influences sibling reaction. If, for example, parents are overprotective and overpermissive with the child with cancer, than the sibling subsystem is equally vulnerable to dysfunction (Minuchin, Baker, Rosman, Lieverman, Milman, & Todd, 1975).

Other stressors in the sibling's life may add to an already high level of stress. A recent divorce or remarriage of a parent, a move, a new baby, a new school, a bully, an alcoholic parent--all are factors that may sometimes cause more concern and distress than having a brother or sister with cancer (Rollins, in press). Outside the home at school and at play, many siblings report being torn between their loyalty to the ill child and the desire to avoid stigma (Chesler & Barbarin, 1987). Often the school is unaware that the child's brother or sister has cancer. In cases where the information is known, teachers may lack understanding about the effects of childhood cancer on the well children. A previously well behaved child may start acting out in the classroom. Grades may plummet. On the other hand, some siblings overachieve with the hope of getting attention.(Sourkes, 1986) While many parents report good support from the school for their child with cancer, many are concerned about school staff's sensitivity to siblings (Chesler & Barbarin, 1987).

Positive Effects.

There has been a recent shift from a focus on psychopathology and disturbance in the sibling to positive adaptation (Sourkes, 1986). While much of what exists in the literature at this time documents the negative effects of having a brother or sister with cancer, a growing number of reports indicate that survivors of childhood cancer (children who survive their illness and parents and siblings of these children) often grow in ways neither we nor they can predict. For example, families indicate they have drawn together, relied on each other in new ways, and love and care for each other more strongly and overtly (Chesler & Barbarin, 1987). Sibling of children with special needs are often very compassionate and sensitive, develop excellent problem solving abilities and coping strategies to use in later life (Powell & Ogle, 1985). Families also report that some siblings experience an increased acceptance of the range of human differences, a less casual attitude toward good health, positive feelings of being responsible for helping their brother or sister, and an understanding of how to communicate effectively with family members and community professionals (Rothery, 1987).

Summary

The chronic illness of a child is a profound experience that has some impact on all members of the family. Research shows evidence that the experience may be most difficult for the healthy siblings in the family, possibly altering development and adjustment in some siblings (Tritt & Esses, 1988). The effects of the crisis of the illness and subsequent reorganization of the family may be more disruptive functionally and emotionally to the well family members than to the patient.

Families coping with crises comprise a population at risk, yet at the same time it is a poulation that is accessible to supportive interventions. Crisis offers the opportunity for growth to occur through the learning and implementation of new coping strategies.

Risk is also involved if the new coping strategies are weak or function for only the more powerful members (Burns, 1985).

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APPENDIX B

INSTRUMENTS

KINETIC FAMILY DRAWING-REVISED (1981)
Spinetta, J., McLaren, H., Fox, R., Sparta, S.

Drawings were completed on $8_{1/2}$ x 11 inch white sheets of paper with colored pencils chosen by each child from a standard set of 10. Erasers were not provided.

The instructions to the subject were standardized. The psychometrist began with the statement, "Draw a picture of everyone in your family doing something." If questions were asked by the subject about the nature of the content, the subject was told, "Draw whatever you like." If the subject asked about drawing himself or herself ("Do I have to draw myself?"), the response was "Draw everyone in you family." On the infrequent occasions when the subjects's drawing was incomplete, the subject was asked, "Is that everyone in your family?" If the response was affirmative, no further instructions were given, even if the drawing was incomplete. If subjects hesitated on the basis of inability to draw well, they were assured that they would not be scored on their artistic ability and that very few of the subjects were true artists.

During the drawing process a psychometrist recorded the following information: subject's name and age, location of the testing, date, identification of the figures (which figure represented which family member), the order in which the figures were drawn, clarification of ambiguous portions of the drawings, the amount of time spent on the drawings, and the subject's spoken comments and actions during the course of the drawing. The subjects were informed before the drawing began as to the content of the observations being recorded.

KFD-R SCORING SYSTEM (negatively valenced)

Nineteen items; total score possible-= 35.

A. Incompleteness of body. The scorer checked for the depiction of all main body parts. All of the following must be present: both arms and legs, torso, head, hands, and feet. An individual's self-image was considered to be reflected in the physical representation of the drawer or his or her family. Portions of the body concealed by a barrier, (e.g., a person sitting behind a desk and thus showing only from the torso upward were still scored. Figures obscured by vehicles were also scored. Max. pts.=2.

0 None (body completely present)
1 Mild (Absence of minor body parts)
2 Severe (absence of major body parts

B. Frequency of missing body parts. The same criteria as for item A (Incompleteness of body) apply for this category. Max. pts.=2.

0 No parts missing
1 Parts missing on one or two people
2 Parts missing on more than two people

C. Cross-outs. Any transparencies or lines drawn through any portion of a person were considered to be cross-outs. A cross-out was viewed as a negative statement toward the figure crossed out, as a form of denial or hostility, reflecting views of the subject. Max. pts.=2.

0 Figures not crossed over
1 Figure partially crossed over
2 Figure totally crossed over

D. Conditions of nature (weather). The scorer checked for any depiction of weather, including rain, sunshine, lightning, clouds, and conditions of darkness or daytime. Context was used to judge this category. For example, snow could be depicted in a recreational and enjoyable theme or as a cold and severe condition.

The perception of environmental forces by the individual was thought to portray internal states or emotions (e.g., and individual portrayed in darkness and harsh weather conditions presumably reflects negative emotions such as loneliness, isolation, or rejection). Portrayal of external states of weather was considered a reflection of emotional tone. Max. pts.=2.

0 Sun shining, no clouds
1 Combination of 2 and 0
2 Rain, snow, darkness

E. Subject portrayal. Of interest was the depiction of the subject in a pejorative manner (e.g., exclusion of subject, incomplete body or face, subject portrayed sitting or lying down, face or body drawn with side view or back turned. Max. pts.=1.

0 Self not portrayed pejoratively
1 Self portrayed pejoratively (parts missing, no face, back turned)

F. Use of color. Use of different colors among the presented set of 10 was monitored. A dearth of color was thought to represent less healthy or adaptive emotional states, as has been discussed in many prior clinical analyses of drawings and other projective techniques. Only generalized emotional states characterizing the subject, no specific negative emotions, were identified. Max. pts.=2.

0 More than two colors
1 Two colors
2 Single color only

G. Use of space on paper. The amount of paper surface used to complete the drawing was determined by first dividing paper into quarters to facilitate estimations of the amount of paper used. Small use of paper suggested emotional impoverishment, probably most related to dysphoria, withdrawal, or isolation. Max. pts.=2.

0 Total page
1 Less than half page
2 Less than a third of page

H. Developmental level. It is recommended that developmental level be scored by an examination of previously scored categories that are developmentally relevant such as body completeness, facial completeness, and size proportion. Max. pts.=1.

0 At or above developmental level
1 Below developmental level

I. Use of stick figures. The depiction of a full body suggests organization and personal integration. Thus incomplete representation of people through stick figures was thought to reflect less healthy psychological states. Max. pt.=1.

0 No stick figures used
1 Stick figures used

J. Facial completeness of subject. The scorer checked for depiction of all essential features of face, including eyes, nose, and mouth. Feelings of adequacy and completeness should be manifested in complete facial features. Max. pts.=2.

0 Complete face
1 Partial face
2 No face

K. Compartmentalization. This item concerns any person in the drawing who is totally contained by lines, for example, separated by boundary lines or enclosed within vechicles or rooms. This category was intended to particularly address subject isolation. Since open family communication channels have been considered important toward adjustment, drawings with partially or fully isolated members are considered reflective of poorer potential communication among family members. Max. pts.=2.

0 Everyone together
1 Some groups separated
2 Everyone in compartments separated by lines

L. Barriers. A barrier is any object or other feature that separates one or more individuals from one or more other people. Barriers can take any form. They need not conform to specific content. Greater barriers between people suggested less likely or less easily attempted communication. Max. pts.=2.

0 No physical obstruction
1 Some groups obstructed
2 Everyone separated by barriers (physical objects or lines)

M. Figure size. Figures should be drawn in correct proportion to one another (children smaller than adults, except in the case of the adolescent, in which the individual may not be smaller than either parent). A realistic and approprate self-image should reflect appropriate perceptions of self in a social environment, with neither overestimations or underestimations of people or their sizes. Therefore size portrayal was considered a reasonable criterion for this category. Max. pts.=2.

0 All figures appropriate size relative to one another
1 Partial figures; some members wrong size
2 No differentiation, or parents smaller than children

N. Used front-back of paper. A false start on one side that is disregarded does not constitute front-back usage. It was thought that the pictoral separation of drawing certain members on opposite sides of the paper represented decreased communication potential. Max. pts.=2.

0 All figures on one side
1 Some on each side of page
2 One person on back side of page alone

O. Exclusions. The absence of any family member(s) from the drawing was noted. A family member was defined as someone who customarily lived in the household. Thus a missing picture of a divorced father was not counted, whereas a mother's live-in companion was scored. This category was primarily concerned with the family's perception of the patient (e.g., symbolic denial of the dying child after a relapse) or the patient's view of himself in the family unit. The process of exclusion and its presumed psychological distancing was considered related to potential family communication process. Max. pts.=2.

0 All family members present
1 Any other family member missing
2 Patient missing

P and Q. Body position of patient and mother. This category and the next communication category, facial postion, were scored only for the patient and the mother to avoid penalizing larger families. Since the mother most commonly accompanied teh patient to medical appointments and most commonly served in a supportive role during these appointments, she was considered the most appropriate figure to score along with the patient. The lying positon was considered reflective of passivity, helplessness, or even death, and thus was less apt to accompany open communication patterns in the family. Max. pts.=4 (2 each for patient and mother).

0 Both mother and patient standing or leaning, but not lying
1 Sitting positon for either mother or patient
2 Lying position or horizontal positon for either mother or patient

R and S. Facial position of patient and mother. This category was also scored for only the mother and patient. The face was scored separate from body position because the orientation of the face may be independent of a significant score for body position. The face has been considered a significant feature by the majority of prior authors evaluating drawings and deserves its own scoring. Communication as an open and potentially healthy process is reflected in openness of facial features. Max. pts.=4 (2 each for patient and mother).

0 Both mother and patient facing toward scorer
1 Side view or profile of figure
2 Figure facing away (e.g., with back of head showing or concealment of face).

Subscales*

	Total score possible
Communication: K, L, N, O, P, Q, R, S	16
Self-image: A, B, C, E, M	9
Emotional tone: D, F, G, H, I, J	10
TOTAL	35

* Order is deliberately scrambled to preclude grouped scoring of set.

Spinetta, J. , McLaren, H., Fox, R., & Sparta, S. (1981). The kinetic family drawing in childhod cancer. In J.J. Spinetta and P.D. Spinetta (Eds.) Living with Childhood Cancer. St. Louis: C.V. Mosby.

Validity and Reliability of KFD-R

When a child is asked for research purposes to draw a picture of a person or of a group of family members, the assumption in interpreting and scoring the drawing is that the child is engaging in a creative problem-solving task whereby he or she selectively chooses particular situational contexts, personal attributes, or styles in which to finish the task. The number of possible components or contextual variables that could occur is so vast that a child is viewed as actively making decisions in constructing a figure or figures arising from internalized valued, experiences, or preferences. Machover (1949) held that the interpretation of a child's drawing is based on the hypothesis that the figure drawn is a unique expression of that child's experiences and preferences. Hammer (1958) held the same view, but added the caution that there may be error variables because of a lack of consistency of response by the same child over time. In addition, those who use drawings in a research or clinical context often find some responses in the drawings whose meaning is difficult if not impossible to interpret. By limiting the use and interpretation of drawings to documentation of those aspects or characteristics of the cld or situation which are chosen for evaluation, researchers limit the potential extent or error variance. It is this limited, controlled, and carefully specified use of drawings that forms the basis for Spinetta, McLaren, Fox, and Sparta's study (1981). Careful and controlled administration of the drawings, in a specifically determined context, increases the validity of the instrument.

On the issue of reliability of children's drawings over time, Machover (1949) stated that the examination of a series of drawings over time by the same individual demonstrates constant structure and form, although content may vary. Thus clothing, details, and accessories (content) may change, but the size of figures, lines, and

placement (form) remains stable. Spinetta et al (1981) used at least 3 drawings per person in 90% of the cases. The drawings were made at different times, to help control potential variation over time. In addition, specific time-related variables (e.g., disease stage, level of pain or physical discomfort, frequency of visits to the clinic, and visibility of effects of the illness and/or treatment) were entered into the analyses to control the specific situational context of the drawing.

Spinetta et al's basic position regarding the reliability and validity of the use of children's drawings in a research context is that careful structuring of hypotheses relative to the drawings, comparison of results with independently derived criterion measures regarding a child's adjustment and attitudes, and careful description of the situational context from which the drawing s and criteria were taken decrease the chance of error or misinterpretation. With careful attention to these critical control elements in the use of children's drawings in a research or measurement context, subjects interpretations are conclusions to empirical verification and justification. Each of the three subscales of the KFD-R (communication, self-image, and emotional tone) was correlated to the other subscales and with the total KFD-R score. The test proved to be internally consistent.

A correlation was performed between each of the combined family KFD-R scores on the four subscales (communication, self-image, emotional tone, and KFD-R total) and each of the six Family Adjustment Scale (FAS) criterion measures. There is a significant negative correlation between the total KFD-R scores for the family members and each of the six FAS criterion measures. This result lends support to the validity of the KFD-R as a measure of a family's subjective response to the cancer experience, relating that response to objectively derived an externally judged criterion measures.

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Scanning a Kinetic Family Drawing

Drawings by children under six years of age are unable to be scored using the KFD-R scoring system. Much valuable information may be gathered by simply scanning a young child's Kinetic Family Drawing with the following questions in mind:

1. What is your first impression?
2. Who and what do you see?
3. What is happening? How do you feel about what is happening?
4. What do you notice about physical intimacy or distance?
5. Is the KFD warm , cold, soft, hard, pleasant, unpleasant?
6. Are people touching or are they shut off from each other?
7. Which members are facing each other?
8. How do people in the KFD feel about their bodies? Are they using their bodies to show off? To hide? To be seductive? Are they proud of their bodies? Ashamed?
9. Who is on the top portion of the drawing? The bottom?
10. Are the KFD "people" happy? Sad? Sadistic? Suffering? Blank? Bored? Rigid? Strong? Involved? Detached? Angry? Subservient? Trusting? Satisfied?
11. How does the group relate? Are they tense or relaxed? What are their messages toward each other? Do you feel love present?
12. Is this a family to which you would like to be a member?

Reference

Burns, R. (1982). Self-growth in families: Kinetic family drawings (K-F-D) research and application. New York: Brunner/Mazel.

BACKGROUND FORM

Confidential
Please do not put your name on this form

1. How many persons currently live in your household? _____

2. Please use the area below to give the age, sex, and relationship to you of all persons who live in your home.

HOUSEHOLD MEMBERS (please write in: self, spouse, child, sister, aunt, etc.)	AGE (write in)	SEX (circle)
a. Self	_____	M F
b. _____	_____	M F
c. _____	_____	M F
d. _____	_____	M F
e. _____	_____	M F
f. _____	_____	M F
g. _____	_____	M F
h. _____	_____	M F

3. What is your marital status? (Check ONE of the following. Write in the number of years that you have been in that status.)

_____Single- (Never Married)

_____Married- (1st Marriage)
How long married? ____

_____Single- (Widowed)
How long widowed? _____

_____Married- (Separated)
How long separated? ____

_____Single- (Divorced)
How long divorced?_____

_____Remarried-
How long? _____

4. Are you currently employed? _____yes _____ no
Occupation _____

5. If married, is your spouse currently employed? ____yes _____no
Occupation _____

6. What kind of cancer does your child have? _____

7. When was he/she diagnosed? _____

8. Do you feel your parents have been supportive of you throughout your child's illness?

MOTHER
___very supportive
___somewhat supportive
___not very supportive
___not applicable

FATHER
___very supportive
___somewhat supportive
___not very supportive
___not applicable

Please estimate distance you live from your parents. _____miles.

9. Do you feel your spouse's parents have been supportive of you throughout your child's illness?

MOTHER
___very supportive
___somewhat supportive
___not very supportive
___not applicable

FATHER
___very supportive
___somewhat supportive
___not very supportive
___not applicable

Please estimate distance you live from your spouse's parents._____miles.

10. What amount is closest to your family's monthly income (after taxes)?

___ Less than $299
___ $300 to $599
___ $600 to 899
____ $900 to $1199
____ $1200 to $1499
____ $1500 to 1799
_____ $1800 to $2099
_____ Over $2100

APPENDIX C

RAW DATA

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	1	2
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	1	1
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	1	0
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	2	0
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	1
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	2	0	0
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	2	0	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	0	0
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	2	0
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	1	1

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	2	2
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	1	0	2
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	1	1
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	1	0	0
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	2	2
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	1	2	1
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	1	2	1

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	4	10	8
Self-image:				
A, B, C, E, M	9	6	4	6
Emotional tone:				
D, F, G, H, I, J	10	5	4	0
TOTAL	35	15	18	14

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	1	2	1
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	2	2
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	2	1
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	0
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	1
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	0	0
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	1	0	1
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	0	0
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	1	0

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	1	0
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	1	0	2
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	1	0	1
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	0	0
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	0	0
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	0	0
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	0	0

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	2	2	1
Self-image:				
A, B, C, E, M	9	6	7	7
Emotional tone:				
D, F, G, H, I, J	10	2	0	1
TOTAL	35	10	9	9

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	2	2
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	2	2
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	1	1
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	1	0	0
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	1
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	0	0
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	2	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	0	0
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	2	0
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	1	1	1

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	2	2	2
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	2	2
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	2	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	1	0	0
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	0	1
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	0	0
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	0	0
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	0	0

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	4	5	4
Self-image:				
A, B, C, E, M	9	8	8	8
Emotional tone:				
D, F, G, H, I, J	10	1	4	0
TOTAL	35	13	17	12

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	2	2
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	2	2
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	1	0
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	0
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	1
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	0	0
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	1	0	0
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	1	2
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	1	0

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	2	2	2
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	2	2
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	0	0
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	1	0
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	1	1	1
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	1	1	2
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	1	2

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	4	7	7
Self-image:				
A, B, C, E, M	9	7	8	7
Emotional tone:				
D, F, G, H, I, J	10	2	1	2
TOTAL	35	13	16	16

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	2	2
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	1	2
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	1	1
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	0
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	1
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	2	2
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	0	0
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	2	2
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	2	0	2

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	2	2	2
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	1	2	2
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	0	0
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	1	0	0
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	1	1	2
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	1	2	2
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	2	2	2

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	9	7	10
Self-image:				
A, B, C, E, M	9	7	7	8
Emotional tone:				
D, F, G, H, I, J	10	1	4	4
TOTAL	35	17	18	22

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	1	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	1	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	1	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	2	X	X
Self-image:				
A, B, C, E, M	9	3	X	X
Emotional tone:				
D, F, G, H, I, J	10	1	X	X
TOTAL	35	6	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	1	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	1	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	1	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	1	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	1	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	4	X	X
Self-image:				
A, B, C, E, M	9	5	X	X
Emotional tone:				
D, F, G, H, I, J	10	1	X	X
TOTAL	35	10	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	0	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	0	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	0	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	1	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	1	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	1	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	2	X	X
Self-image:				
A, B, C, E, M	9	1	X	X
Emotional tone:				
D, F, G, H, I, J	10	1	X	X
TOTAL	35	4	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	1	2	2
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	2	2
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	0	1
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	1
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	1
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	0	0
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	0	0
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	0	1
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	0	0

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	0	1	2
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	0	0	0
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	0	0
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	1	1	1
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	1	0
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	0	1
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	0	0

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	1	3	4
Self-image:				
A, B, C, E, M	9	5	5	6
Emotional tone:				
D, F, G, H, I, J	10	1	0	2
TOTAL	35	7	8	12

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	0	2	0
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	0	2	0
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	1	0
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	1	0	1
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	1	0
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	0	0
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	0	0
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	0	1
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	1	0

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	0	2	1
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	0	0	2
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	0	0
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	2	0
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	2	0
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	0	0
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	0	0

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	0	7	1
Self-image:				
A, B, C, E, M	9	0	6	2
Emotional tone:				
D, F, G, H, I, J	10	1	0	1
TOTAL	35	1	13	4

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	1	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	2	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	1	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	1	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	1	X	X
Self-image:				
A, B, C, E, M	9	4	X	X
Emotional tone:				
D, F, G, H, I, J	10	3	X	X
TOTAL	35	8	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	2	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	1	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	1	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	1	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	1	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	1	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	2	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	1	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	7	X	X
Self-image:				
A, B, C, E, M	9	6	X	X
Emotional tone:				
D, F, G, H, I, J	10	4	X	X
TOTAL	35	17	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	0	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	0	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	1	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	1	X	X
Self-image:				
A, B, C, E, M	9	3	X	X
Emotional tone:				
D, F, G, H, I, J	10	1	X	X
TOTAL	35	5	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	1	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	1	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	0	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	1	X	X
Self-image:				
A, B, C, E, M	9	4	X	X
Emotional tone:				
D, F, G, H, I, J	10	1	X	X
TOTAL	35	6	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	2	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	2	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	0	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	0	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	0	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	1	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	1	1	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	2	2	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	0	0	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	1	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	1	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	1	2	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	0	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	2	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	4	9	X
Self-image:				
A, B, C, E, M	9	6	5	X
Emotional tone:				
D, F, G, H, I, J	10	0	1	X
TOTAL	35	10	15	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	0	1	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	0	1	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	0	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	0	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	1	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	0	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	0	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	0	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	0	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	0	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	0	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	0	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	0	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	0	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	1	0	X
Self-image:				
A, B, C, E, M	9	3	3	X
Emotional tone:				
D, F, G, H, I, J	10	0	1	X
TOTAL	35	4	4	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	1	1	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	2	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	0	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	0	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	2	2	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	2	1	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	1	1	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	1	1	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	0	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	0	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	1	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	2	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	0	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	1	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	1	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	0	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	0	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	0	3	X
Self-image:				
A, B, C, E, M	9	3	5	X
Emotional tone:				
D, F, G, H, I, J	10	0	5	X
TOTAL	35	3	13	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	1	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	1	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	3	X	X
Self-image:				
A, B, C, E, M	9	7	X	X
Emotional tone:				
D, F, G, H, I, J	10	1	X	X
TOTAL	35	11	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	1	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	1	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	1	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	1	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	5	X	X
Self-image:				
A, B, C, E, M	9	7	X	X
Emotional tone:				
D, F, G, H, I, J	10	1	X	X
TOTAL	35	13	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	1	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	1	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	1	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	2	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	2	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	2	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	1	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	2	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	2	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	9	X	X
Self-image:				
A, B, C, E, M	9	7	X	X
Emotional tone:				
D, F, G, H, I, J	10	4	X	X
TOTAL	35	20	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	1	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	1	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	2	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	1	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	1	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	2	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	2	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	2	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	2	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	2	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	2	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	14	X	X
Self-image:				
A, B, C, E, M	9	7	X	X
Emotional tone:				
D, F, G, H, I, J	10	1	X	X
TOTAL	35	22	X	X

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	1	1	2
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	2	2
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	1	0
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	0
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	1
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	0	2
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	0	0
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	2	0	0
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	0	1

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	0	1
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	0	0	2
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	0	0
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	0	0
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	0	0
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	2	0	0
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	0	0

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	3	0	2
Self-image:				
A, B, C, E, M	9	5	5	7
Emotional tone:				
D, F, G, H, I, J	10	2	0	2
TOTAL	35	10	5	11

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	2	2	1
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	2	2	2
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	0	0	0
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	0
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	0	1
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	0	0
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	0	1
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	0	0
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	0	1

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	1	0	1
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	1	2
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	0	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	0	0
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	0	1
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	0	1
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	0	2
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	0	2

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	1	0	8
Self-image:				
A, B, C, E, M	9	6	5	6
Emotional tone:				
D, F, G, H, I, J	10	0	0	1
TOTAL	35	7	5	15

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	0	0	0
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	0	0	0
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	1	1
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	0	0
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	1	1	0
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	1	1
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	0	0
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	0	0
I. Use of stick figures 0 No stick figures used 1 Stick figures used	1	0	0
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	1	1	0
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	2	0	0

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	2	0	0
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	0	1	2
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	2	0	0
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	2	0	0
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	2	0	0
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	2	0	0
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	2	0	0
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	2	0	0

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	16	0	0
Self-image:				
A, B, C, E, M	9	2	3	3
Emotional tone:				
D, F, G, H, I, J	10	2	2	1
TOTAL	35	20	5	4

KFD-R SCORING SYSTEM (negatively valenced)	Drawings 1st	2nd	3rd
A. Incompleteness of body 0 None (body completely present) 1 Mild (Absence of minor body parts) 2 Severe (absence of major body parts	0	X	X
B. Frequency of missing body parts 0 No parts missing 1 Parts missing on one or two people 2 Parts missing on more than two people	0	X	X
C. Cross-outs 0 Figures not crossed over 1 Figure partially crossed over 2 Figure totally crossed over	1	X	X
D. Conditions of nature (weather) 0 Sun shining, no clouds 1 Combination of 2 and 0 2 Rain, snow, darkness	0	X	X
E. Subject portrayal 0 Self not portrayed pejoratively 1 Self portrayed pejoratively	0	X	X
F. Use of color 0 More than two colors 1 Two colors 2 Single color only	0	X	X
G. Use of space on paper 0 Total page 1 Less than half page 2 Less than a third of page	0	X	X
H. Developmental level 0 At or above developmental level 1 Below developmental level	0	X	X
I. Use of stick figures 0 No stick figures used 1 Stick figures used	0	X	X
J. Facial completeness of subject 0 Complete face 1 Partial face 2 No face	0	X	X
K. Compartmentalization 0 Everyone together 1 Some groups separated 2 Everyone in compartments	0	X	X

	Drawings 1st	2nd	3rd
L. Barriers 0 No physical obstruction 1 Some groups obstructed 2 Everyone separated by barriers	0	X	X
M. Figure size 0 All figures appropriate size 1 Partial figures; some wrong size 2 No differentiation	2	X	X
N. Used front-back of paper 0 All figures on one side 1 Some on each side of page 2 Person on back side of page alone	0	X	X
O. Exclusions 0 All family members present 1 Any other family member missing 2 Patient missing	0	X	X
P. Body position of patient 0 Patient standing 1 Patient sitting 2 Patient lying	0	X	X
Q. Body position of mother 0 Mother standing 1 Mother sitting 2 Mother lying	0	X	X
R. Facial position of patient 0 Front of patient facing viewer 1 Side of patient facing viewer 2 Back of patient facing viewer	0	X	X
S. Facial position of mother 0 Front of mother facing viewer 1 Side of mother facing viewer 2 Back of mother facing viewer	0	X	X

Subscales	Total score possible			
Communication:				
K, L, N, O, P, Q, R, S	16	0	X	X
Self-image:				
A, B, C, E, M	9	3	X	X
Emotional tone:				
D, F, G, H, I, J	10	0	X	X
TOTAL	35	3	X	X

APPENDIX D

SUPPLEMENTARY TABLES

Table I

Descriptive Characteristics of Subjects with Cancer

(N=17)

	Frequency	Percentage
Age in years (M=7.59)		
1	1	5.88%
3	1	5.88%
4	1	5.88%
5	2	11.76%
6	2	11.76%
7	4	23.53%
8	1	5.88%
9	2	11.76%
13	1	5.88%
14	1	5.88%
18	1	5.88%
Sex		
Males	10	58.82%
Females	7	41.18%

(Table Continues)

Descriptive Characteristics of Subjects with Cancer

Diagnosis

ALL	9	52.94%
Wilms tumor	2	11.76%
Rhabdomyosarcoma	1	5.88%
Colon cancer	1	5.88%
Neuroblastoma	1	5.5886%
T-Cell Leukemia	1	5.5886%
Osteogenic sarcoma	2	11.76%

Date of diagnosis

1984	2	12.5%
1985	4	25%
1986	6	37.5%
1987	3	18.75%
1988	1	6.25%

Note: 1 no response

Table II

Descriptive Characteristics of Sibling Subjects

(N=26)

	Frequency	Percentage
Age in years (M=8.27)		
2	3	11.54%
3	2	7.69%
4	2	7.69%
5	1	3.85%
6	3	11.54%
7	1	3.85%
8	2	7.69%
9	3	11.54%
10	2	7.69%
11	1	3.85%
12	2	7.69%
14	2	7.69%
15	1	3.85%
24	1	3.85%
Sex		
Males	9	34.62%
Females	17	65.38%

Table III

Descriptive Characteristics of Parents

(N=29)

	Frequency	Percentage
Age in years (M=33.9)		
26	2	6.9%
27	3	10.3%
28	2	6.9%
29	1	3.5%
30	2	6.9%
31	1	3.5%
32	3	10.3%
33	1	3.5%
34	1	3.5%
35	2	6.9%
36	1	3.5%
37	1	7.5%
38	1	3.5%
39	1	3.5%
40	3	10.3%
41	2	6.9%
43	1	3.5%
45	1	3.5%

(Table Continues)

Descriptive Characteristics of Parents

Marital status		
First marriage	10	58.82%
Remarried	4	23.53%
Single parent	3	17.65%

Table IV

Descriptive Characteristics of Household

(N=17)

	Frequency	Percentage
Number in household		
(M=4.35)		
3	4	23.53%
4	5	29.41%
5	6	35.29%
6	2	11.76%
Number of siblings		
in household (M=1.59)		
1	9	52.94%
2	6	35.29%
3	2	11.76%

(Table Continues)

Descriptive Characteristics of Household

Monthly income		
(M=$1200-$1499)		
$300-$599	1	6.25%
$600-$899	2	12.5%
$900-$1199	1	6.25%
$1200-$1499	4	25%
$1500-$1799	2	12.5%
$1800-$2099	1	6.25%
Over $2100	5	31.25%
Note: 1 no response		
Employment		
Working mothers	11	55.56%
Unemployed fathers	2	11.11%

Table V

Individual KFD-R Profiles

Subjects*	1st Score	2nd Score	3rd Score
2a			
Communication	4	10	8
Self-image	6	4	6
Emotional tone	5	4	0
Total	15	18	14
2b			
Communication	2	2	1
Self-image	6	7	7
Emotional tone	2	0	1
Total	10	9	9
2c			
Communication	4	5	4
Self-image	8	8	8
Emotional tone	1	4	0
Total	13	17	12

(Table Continues)

Individual KFD-R Profiles

3a			
Communication	4	7	7
Self-image	7	8	7
Emotional tone	2	1	2
Total	13	16	16
3b			
Communication	9	7	10
Self-image	7	7	8
Emotional tone	1	4	4
Total	17	18	22
4a			
Communication	2	X	X
Self-image	3	X	X
Emotional tone	1	X	X
Total	6	X	X
4b			
Communication	4	X	X
Self-image	5	X	X
Emotional tone	1	X	X
Total	10	X	X

(Table Continues)

Individual KFD-R Profiles

4c

Communication	2	X	X
Self-image	1	X	X
Emotional tone	1	X	X
Total	4	X	X

5a

Communication	1	3	4
Self-image	5	5	6
Emotional tone	1	0	2
Total	7	8	12

5b

Communication	0	7	1
Self-image	0	6	2
Emotional tone	1	0	1
Total	1	13	4

05a

Communication	1	X	X
Self-image	4	X	X
Emotional tone	3	X	X
Total	8	X	X

(Table Continues)

Individual KFD-R Profiles

05b			
Communication	7	X	X
Self-image	6	X	X
Emotional tone	4	X	X
Total	17	X	X
06a			
Communication	1	X	X
Self-image	3	X	X
Emotional tone	1	X	X
Total	5	X	X
07a			
Communication	1	X	X
Self-image	4	X	X
Emotional tone	1	X	X
Total	6	X	X
08a			
Communication	4	9	X
Self-image	6	5	X
Emotional tone	0	1	X
Total	10	15	X

(Table Continues)

Individual KFD-R Profiles

08b

Communication	1	0	X
Self-image	3	3	X
Emotional tone	0	1	X
Total	4	4	X

09a

Communication	0	3	X
Self-image	3	5	X
Emotional tone	0	5	X
Total	3	13	X

09b

Communication	3	X	X
Self-image	7	X	X
Emotional tone	1	X	X
Total	11	X	X

010b

Communication	5	X	X
Self-image	7	X	X
Emotional tone	1	X	X
Total	13	X	X

(Table Continues)

Individual KFD-R Profiles

010c			
Communication	9	X	X
Self-image	7	X	X
Emotional tone	4	X	X
Total	20	X	X
010d			
Communication	14	X	X
Self-image	7	X	X
Emotional tone	1	X	X
Total	22	X	X
011a			
Communication	3	0	2
Self-image	5	5	7
Emotional tone	2	0	2
Total	10	5	11
011b			
Communication	1	0	8
Self-image	6	5	6
Emotional tone	0	0	1
Total	7	5	15

(Table Continues)

Individual KFD-R Profiles

011c

Communication	16	0	0
Self-image	2	3	3
Emotional tone	2	2	1
Total	20	5	4

012b

Communication	0	X	X
Self-image	3	X	X
Emotional tone	0	X	X
Total	3	X	X

---

* Numbers followed by "a" are children with cancer. Numbers followed by "b", "c", or "d" are siblings of children with cancer.

X Unable to obtain additional drawings.

Table VI

Family Profiles of KFD-R Scores

Subjects*	1st Score	2nd Score	3rd Score
2a	15	18	14
2b	10	9	9
2c	13	17	12
3a	13	16	16
3b	17	18	22
4a	6	X	X
4b	10	X	X
4c	4	X	X
5a	7	8	12
5b	1	13	4
05a	8	X	X
05b	17	X	X
06a	5	X	X

(Table Continues)

Family Profiles of KFD-R Scores

07a	6	X	X
08a	10	15	X
08b	4	4	X
09a	3	13	X
09b	11	X	X
10b	13	X	X
010c	20	X	X
010d	22	X	X
011a	10	5	11
011b	7	5	15
011c	20	5	4
012b	3	X	X

* Numbers followed by "a" are children with cancer. Numbers followed by "b", "c", or "d" are siblings of children with cancer.

X Unable to obtain additional drawings.

Table VII

Scoring Data Omissions

The following subjects were too young for KFD-R scoring:

1a

1b

6a

6b

01a

01b

02a

02b

04a

06b

The following subjects were unavailable or too young for testing:

2d

6c

04b

04c

05c

07b

010a

012a

APPENDIX E

SUMMARY OF ANALYSES

APPENDIX E

SUMMARY OF ANALYSES

Analysis of Data from Demographic Questionnaire

While not every family member participated, seventeen families of children with cancer took part in this study. Over one-third of the sample have 5 people living in the household. The mean number of persons per household is 4.35. The majority of the families (52.94%) have a two-child family, the current trend in America today. While 31.25% of the families have a monthly income of over $2100, a disturbing 18.75% have incomes hovering at or below the poverty level. This fact, while disconcerting, is not surprising. The study took place in a state that is suffering from its largest economic slump in decades. The majority (55.56%) of the mothers are employed outside the home. Two of the fathers are unemployed.

Twenty-nine parents are represented in the 17 families. The mean age for parents is 33.9 years. Ages range from 26 to 45 years of age. For 10 (58.82%) of the couples, this is their first marriage. For close to a quarter (23.53%), this is a remarriage. There are 3 single parent families.

Ages of the children with cancer range from 1 to 18 years, with a mean age of 7.59 years. There are 10 males and 7 females. The majority of the children (52.94%) have a diagnosis of Acute Lymphocytic Leukemia, the most common and most treatable form of childhood cancer. Two children have Wilms Tumor; two have osteogenic sarcoma. Rhabdomyosarcoma, colon cancer, neuroblastoma, and T-cell leukemia each claim one child. Over one-third of the children (37.5%) were diagnosed in 1986. Two children were diagnosed in 1984. The newest diagnosis was 5 weeks prior to the study.

Siblings range in age from 2 to 24 years. The mean age is 8.29 years. There are 9 males and 17 females. In all but one family, the age difference between at least a pair of siblings places them in the high-access category.

Analysis of Data from KFD-R Scores

On the KFD-R, individual scores vary considerably from pretest, posttest, and second posttest in those families participating in the one-time intervention as well as those who had not. As much as a 16 point difference is noted between a series of individual scores. The highest total score is 22, indicating a maladaptive drawing. This score was assigned to drawings by a 7 year old male and a 6 year old female. Both of the subjects are siblings. The mean score for sibling's drawings is 11.06, slightly higher than the mean score for the children with cancer (10.65). The highest score for a subject with cancer was 18 points. The lowest score--1 point--was given for a drawing by an 11 year old sibling. The lowest score for a child with cancer is 3 points. In some cases scores increased, others decreased, others increased and decreased, or decreased and increased. Scores exhibit the same fluctuation when subjects from the same family are grouped and compared (See Tables V and VI, Appendixes D).

Due to the small sample size, no pattern could be determined. Because 10 of the subjects were under the age of 6, the choice of the KFD-R was probably unwise. Eight additional subjects were either too young to test or unavailable for testing, decreasing the sample size even further. Moreover, the KFD-R is sensitive to how the subject feels at a particular moment in time, which--judging from the wide range of scores--may not have been useful in a study of a relatively short duration.

Data from the drawings and discussions with siblings confirm previous sibling research findings, as well as reflect current social changes that will ultimately increase the importance of the sibling relationship itself.

APPENDIX F

CORRESPONDENCE WITH FAMILIES

oth Oklahoma Teaching Hospitals 800 Northeast 13th P.O. Box 26307 Oklahoma City, OK 73126

Dear Parent:

The Hematology/Oncology Clinic is offering a special program for brothers and sisters of children with cancer. We hope that your children will be able to participate in this program. Having a brother or sister with cancer can be stressful for the healthy children in the family. Sometimes children are curious about cancer or about our clinic or they may have a variety of different feelings about their brother or sister's illness that they don't fully understand. The program, "Sibling Day", is designed to help answer some of the questions that healthy children may have about their brother or sister's cancer.

The program will last about 2½ hours. It will consist of basic information about cancer, a film about having a brother or sister who has cancer or another chronic illness, a tour of our clinic and x-ray lab, and a group discussion. Two weeks prior to the program, after the program, and two weeks later, we will ask the children to draw a picture of their family as a way to evaluate the effectiveness of the program. We will let parents know about their children's experiences in the program.

We would like as many children as possible to attend this program because we feel it would be very helpful for them, so we need to know what would be most convenient for your family. If you could complete this form and return it in the enclosed envelope, it will help us to plan the program.

1. Do you think you would like to participate in this program?

   _____yes _____no

2. Which days and times would be best for you?

   _____Thursday mornings (9-11:30)

   _____Thursday afternoons (4-6:30)

   _____Saturday mornings (9-11:30)

   _____another time (day_____time_____)

3. What would keep you from being in the study?

   _____transportation _____cost _____time

   _____work _____need more information

   _____other (_____)

A component of the Department of Human Services and affiliated with the University of Oklahoma Health Sciences Center

If you would like more information about this opportunity, please call Dr. Heather Huszti (271-5311) or Joan Boswell, R.N. (271-4412).

Thank you very much.

Sincerely yours,

Heather Huszti, Ph.D.

Heather Huszti, Ph.D.
Post Doctoral fellow

Joan Boswell, R.N.
Head Nurse
Hematology/Oncology

tb

HEM-ONC SUPPORT MEETING
March 29, 1988
7:00 PM

If you are interested in the recent changes in the hospital's billing and collection system and available financial aid, then you need to be at the upcoming Support Group Meeting. This meeting will allow parents to ask direct questions to the Director of the hospital and Director of Patient Accounting. This will be a positive opportunity to be heard by those who can make a difference. This will also be the last meeting for a while in which the topic or discussion will focus on billing.

If you are having problems and are not getting results from the billing staff, see or call Pat Wimberly, Patient Representative for help. She not only knows the hospital but she also has the experience of being a Hem-Onc mom.

***

First of all, a big thank you to all the off-treatment patients and parents who attended the February parent meeting. You were all very inspiring!

We understand the meeting seemed to turn more toward hospital technicalities which was unintended. Therefore, we would like to schedule another more informal gathering which will allow for more sharing of experiences among families on and off treatment.

We graciously invite you all to come again!

Janna Jahansouz

***

When the Parent Group Meetings began in October, we very carefully avoided using the word "support" in describing the group. Now, I think it's time we admitted it - this is a support group. But not just a parent group. This is a group for parents, friends, former patients, grandparents. I think a more appropriate description would be Hem-Onc Support Meeting and anyone wanting to attend is very welcome to come.

Pam Murphy

SIBLING STUDY

The OPCA is helping with a study being done by Nancy Stevens and Judy Rollins of Tulsa, involving children with cancer and their brothers and sisters. On March29th during the Hem-Onc Support Group Meeting from 7:00 - 9:00 pm Judy and Nancy will be having some preliminary activities in preparation for a brother-sister day at the clinic in April.

Any parents who would like to have their children participate in this study can bring them to the Group Meeting. While the parents meet, the children will be supervised and involved in the activities in a room nearby. We will be providing refreshments and the children are assured of having a good time.

Any parents who would like to participate but cannot make the meeting can contact MadaIyn McCollom at 789-6783 [after 6] for information about alternative dates.

Ms. Rollins is a pediatric R.N. who has worked with children with cancer and their families in the past. We feel that the issued involving brothers and sisters of children with cancer is an important one and this is why we are helping with this study. We hope that as many as possible are able to participate.

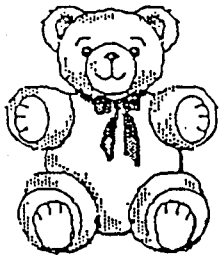
OPCA BEREAVED PARENTS GROUP

During the last decade, enormous strides have been made in the treatment of childhood cancers. More and more children are now surviving certain types of these diseases. Unfortunately, many children do not survive. While there are various bereavement groups in the community, these do not specifically address the needs of families who have lost a child to cancer. The OPCA feels that these families have special needs.

Therefore, we are sponsoring a BEREAVED PARENTS GROUP. This group will meet on a regular monthly basis, the 1st Thursday of each month. The first meeting will be April 7th at 7:00 pm at St. Patrick's Church, 2021 N. Portland. Any parent who has lost a child to cancer is welcome to attend. For more information you may call:

Dee Ricketts - 424-6873
Danny Cavett - 271-5758
Nancy Guziec - 722-9514

A SPECIAL DAY FOR BROTHERS AND SISTERS



Having a brother or sister with cancer can be stressful for the healthy children in the family. Sometimes children are curious about cancer or about our clinic or they may have a variety of different feelings about their brother or sister's illness that they don't fully understand. We would like to invite your children to participate in a program that we feel would be very helpful to them.

The Hematology/Oncology Clinic is offering a special program, **"Sibling Day"**, for brothers and sisters of children with cancer. The day is designed to help answer some of the questions that healthy children may have about their brother or sister's cancer. The program will last about 2 hours and include:

- basic information about cancer
- a film about having a brother or sister who has cancer or another chronic illness
- a tour of our clinic and x-ray lab
- a group discussion
- refreshments and prizes

Two weeks prior to the program, after the program, and two weeks later, we will ask the children to draw a picture of their family as a way to evaluate the effectiveness of the program. We will let parents know about their children's experiences in the program. If you have questions, please call Heather Huszti at 271-5311. We hope that your children will be able to participate in this program. We are offering "Sibling Day" twice (**April 16 and April 30**) so that more children will be able to attend the program.

Please choose the Saturday that is most convenient for you and return this portion to the clinic.

Saturday, April 16 ____
Saturday, April 30 ____

In order to obtain a pre-Sibling Day drawing, please bring your children to the next Oklahoma Pediatric Cancer Association meeting on **Tuesday, March 29.** You need not be a member of OPCA. If you are unable to attend March 29, we will contact you to arrange a more convenient time.

Names and ages of children_____
_____
_____
_____
_____
Address_____
Phone _____
Please check one of the following:
Yes, I will be able to bring my children on Tuesday, March 29_____
Please contact me to set up a more convenient time_____

APPENDIX G

PILOT STUDY

APPENDIX G

PILOT STUDY

The pilot study provided the investigator with the opportunity to practice the testing process in an unfamiliar setting and to "run through" a mock Sibling Day to assess timing and other program features.

Subjects

Four children, ages 4 to 7 years of age, served as subjects for the pilot study. The sample was 50% male and 50% female. All were children of staff members at the children's hospital where two of the Sibling Days were scheduled to take place. All of the children were healthy and, for those who had siblings, the siblings were healthy.

Procedure

The investigator explained the study to the parents and the subjects. Consent forms were given to parents for signatures. In most cases the parent read the child consent form to the subject. All agreed to participate in the program.

Individually, the subjects produced a kinetic family drawing. The clinic nurse discussed cancer and led a tour of the clinic. The subjects returned to watch "My Brother is Sick." This film and "Childhood Cancer: The Sibling's Perspective" had been previewed and approved by a reviewing committee of two psychologists, two pediatric nurses (the investigators), and a parent of a child with cancer.

A short discussion followed the film. The subjects enjoyed snacks and a group art activity. A few small surprises were presented to the children in appreciation for their participation in the pilot study.

Discussion

As a result of the pilot study two changes were made. First, the children did not like using colored pencils. They complained that it was difficult to see the colors. When asked what would be good to use, they recommended colored markers. A decision was made to use watercolor markers in the same colors as the pencils.

Second, it did not take as long as anticipated to complete all of the activities. The time allocated for Sibling Day was changed from 2 1/2 hours to 2 hours.

APPENDIX H

CONSENT LETTERS

CONSENT FORM

It has long been recognized that a very unique relationship exists between siblings (brothers and sisters). Your children are invited to participate in a research study designed to provide information about this relationship when one of the children has cancer. You will be asked to complete a brief Information Questionnaire. Your child with cancer will be asked to produce a simple drawing on three separate occasions over an eight week period. The process should take no more than 5 to 10 minutes each time. Your healthy child will be asked to participate in a "Sibling Saturday" in addition to producing the simple drawing on three separate occasions.

"Sibling Saturday" will consist of the following activities: 1. A film concerning being a sibling of a child with cancer; 2. A tour of the clinic, x-ray and the lab led by clinic staff; 3. Group "rap sessions" led by registered nurses with experience working with children with cancer and their families, counseling expertise, and graduate training in family therapy; 4. An expressive art session led by the researcher, a registered nurse with experience in art therapy with children.

A supportive setting with experienced registered nurses should reduce the risk, such as crying or discomfort felt by your child in the discussion or expression of perhaps some sensitive feelings. Sibling Saturday is expected to provide a positive experience for your child.

You will be given feedback at the conclusion of the project. Information obtained from this study will be included in a Master's thesis at Oklahoma State University and possibly subsequent articles in professional journals. Confidentiality will be insured by the use of a number code and omiting children's names and the name of the clinic and location where your child is receiving treatment. Drawings may appear, again, without identifying information. Information will be kept in a locked filing cabinet in the researcher's home. All identifying information will be destroyed immediately following the completion of the project.

You or your children will be free to withdraw permission at any time during the study. Refusal to participate will involve no penalty or loss of benefits to which you or your children are entitled. If you have any questions during the course of this study, please feel free to contact me at any time at (918) 357-2061.

Judy Rollins, R.N., Graduate Student, Department of Family Relations and Child Development, Oklahoma State University, Stillwater, OK.

The study has been explained to me and I have had the opportunity to ask questions. My children are aware of the diagnosis of cancer. I voluntarily consent to having my children participate in this project.

Signature of parent or legal guardian Date

I acknowledge that the nature and purpose of this research study, possible alternative methods of treatment, the risks involved, the possible complications, or unintended results were fully explained to the subject or his/her respresentative by me before the patient consented.

Investigator Date

Witness Date

CONSENT FORM

I would like to be in the study that _____has explained to me. I understand that I can stop any time I want and nothing bad will happen to me. No one will be mad or disappointed.

_____ _____

Participant Date Investigator Date

University of Oklahoma Health Sciences Center and Oklahoma Children's Memorial Hospital

Authorization to Participate in a Sibling Day for Pediatric Cancer Patients

I, I for my child _____ voluntarily agree for my child _____
(parent or legal guardian) (name of minor)
to participate in this study entitled, "Evaluation of a Sibling Day for Pediatric Cancer Patients". This study is under the supervision of Patrick J. Mason, Ph.D., and is being conducted by Heather Huszti, Ph.D.

1) Purpose. The purpose of this study is to: a) study the effects a child with cancer has on the sibling (brothers and sisters) relationships, and b) evaluate family members' perceptions of family communication and cohesiveness before and after a "Sibling Day for Pediatric Cancer Patients".

2) Description of the study. I understand that my family will be randomly (by chance) assigned to one of two groups. In order to evaluate the effectiveness of the program, one group will receive the Sibling Day program in 2 weeks, while the other group will complete the questionnaires and receive the program in 4 weeks. I will be asked to complete a brief Information Questionnaire, and an additional questionnaire containing approximately 90 questions regarding family coping. My child with cancer will be asked to produce a simple drawing on three separate occasions over an four week period. The drawing will take 5 to 10 minutes each time. At least one of my healthy child(ren) will be asked to participate in a "Sibling Day" in addition to producing the simple drawing on three separate occasions. The "Sibling Day" will be held at the clinic and will last approximately 2½-3 hours. The day will consist of the following activities: An age appropriate film concerning being a sibling of a child with cancer; a tour of the clinic, x-ray facilities, and the lab led by clinic staff; a group discussion led by registered nurses and other health care professionals with experience working with children with cancer and their families; an expressive art session led by a registered nurse with experience in art therapy with children. I will be given feedback about my child's experiences in the program at the conclusion of the program by one of the investigators.

3) Benefits. I understand that my children and my family may benefit from involvement in Sibling Day. My child may learn more about his or her sibling's illness and about the types of feelings that healthy siblings often have about a brother or sister with cancer. This experience may help my family discuss their feelings about the cancer treatment. Information gained from this project will help professionals working with families who have a child with cancer to treat the special needs of the siblings of cancer patients more effectively.

4) Alternative Procedures. If I choose not to participate in this study, my family will continue to receive the usual comprehensive care for cancer received in our clinic.

5) Subject Assurance. Whereas no assurance can be made concerning any results that may be obtained (because results from investigational studies cannot be predicted with certainty), the principal investigator will take every precaution consistent with the best ethical practices used in research.

By signing this consent form, I know that I have not waived any of my rights or released this institution from liability for negligence. I may revoke my consent and withdraw from this study at any time without penalty or loss of benefits. My treatment and relations with the Oncology Center staff and the University of Oklahoma Health Sciences Center, now and in the future, will not be affected in any way if I refuse to participate, or if I enter the study and later withdraw.

It is clear to me that no compensation will be available to me from the State of Oklahoma Health Sciences Center or its employees unless I otherwise qualify for the University's health insurance or for other employee or student benefits. I understand that if I am so injured, medical facilities and treatment will be available to me. However, I will be required to pay a reasonable fee for such care. This does not mean that I could not receive medical benefits if otherwise entitled. I understand that if I have any questions or desire further information concerning the availability of compensation or medical care, I may contact Andy Sullivan, M.D., OCMH Chief of Staff at 271-4790.

RECORDS OF THIS STUDY WILL BE KEPT CONFIDENTIAL WITH RESPECT TO ANY WRITTEN OR VERBAL REPORTS, MAKING IT IMPOSSIBLE TO IDENTIFY ME OR ANY MEMBER OF MY FAMILY INDIVIDUALLY. RESULTS OF THE STUDY WILL NOT BE DOCUMENTED ON MY CHILD'S HOSPITAL CHART.

If I have any questions about the research procedures, I will call Dr. Mason at (405) 271-5311 or Dr. Huszti at 271-4412 or 755-5666. If I have questions about my right as a research subject, I may take them to the Director of Research Administration, University of Oklahoma Health Sciences Center, Room 115, Library Building, telephone number: (405) 271-2090.

I have read the informed consent document. I understand its contents and I freely consent to participate in this study under the conditions described in this document. I understand that I will receive a copy of this signed consent form.

Parent or legal guardian Date	Investigator Date
Parent or legal guardian Date	Witness Date

CONSENT FORM

I would like to be in the study that has been explained to me. I know that I will draw a picture three different times. I know that I will be in a group of other children and we will watch a film, tour the clinic, and talk about how I feel about having a brother or sister who has cancer. This program can be fun and I can learn more about my feelings and about my brother or sister's illness. I understand that I can stop any time I want to and no one will be mad or disappointed. If I want to talk about the program later, I can talk to my parents or to Dr. Mason or Dr. Heather Huszti (271-5311).

_____ _____

Participant Date

_____ _____

Investigator Date

APPENDIX I

PROPOSED STUDY

APPENDIX I

PROPOSED STUDY

Altering Mood in Children with Cancer Through Intervention with Their Healthy Siblings

Only recently has concern been expressed about the effects of pediatric cancer on the sibling relationship. Described by researchers as the "forgotten ones" (Sourkes, 1986), a growing number of studies are now centering on siblings of a child suffering from chronic illness or life-threatening disease. These studies indicate that often siblings experience more stress than any other member of the family.

A small number of professionals working in pediatric oncology clinics have recognized the unmet needs of healthy siblings and have inaugurated interventions such as sibling support groups or "Sibling Days." Those interventions that include an evaluation component indicate that intervention is helpful in reducing stress in the healthy siblings.

Problem Statement

While these studies are beginning to focus on the impact of the sick child on the healthy sibling, much of the interaction between the siblings themselves has been ignored. The question of whether or not the healthy sibling's interaction in the sibling subsystem will result in changes in the child with cancer has not yet been adequately addressed. Focusing only on one member of the subsystem ignores the bidirectionality of a complex dyad (McKeever, 1983). Can something as simple as a one-time intervention with healthy siblings improve family communication? It may be possible that increased communication leads to brightening not only the healthy sibling's mood,

but that of the ill child's as well. If, indeed, siblings act and react to one another in both constructive and destructive ways and possibly mirror each others moods and perceptions, can professionals working with such families use this knowledge to provide more comprehensive care not just for siblings, but for the children with cancer, too ?

The sibling relationship is typically the longest relationship that any human being can share with another. Because it is presumed that the healthy sibling(s) will carry the experience and memories of the child with cancer longer than any other family member, it is of vital importance that this experience be fully examined.

Objectives

The overall objective of this study was to compare the emotional mood of children with cancer and that of their healthy siblings with their mood after a one-time intervention with the healthy siblings. During this one-time "Sibling Saturday" intervention, siblings spent a day at the oncology clinic learning about cancer and exploring what the experience means to them. The study sought to determine if the resulting interaction between siblings would result in change of mood in the children with cancer who had not experienced the intervention. Would they be able to benefit indirectly through their healthy siblings?

The study compared the healthy siblings' sense of isolation and perception of family communication with that of their ill siblings', both before and after intervention work with the healthy siblings. Emotional mood was assessed in the healthy siblings and in their ill brother or sister before and after intervention, and the results were compared with an emphasis on similarities and differences in their perceptions of the emotional tone of their families.

Because the experiences of siblings of the pediatric cancer patient may be extrapolated to siblings of children with other life-threatening diseases (Sourkes, 1986), as a final goal, it was hoped that the results of this study would act as a stimulus for

more sibling research. Family research may well prove useful to legislators as well as those health care professionals who have the power and the means to determine policies and practices influencing the quality of life, not only for the child with cancer, but for other members of the family system as well.

Hypotheses

Parents must often divide their time between hospital and home, often leaving the siblings with a friend or relative, or sometimes alone. Although an increasing number of hospitals are recognizing the benefits of sibling visitation, many pediatric cancer patients receive specialized treatment in hospitals or clinics often a great distance from home. This may result in the healthy sibling having very little contact with the brother or sister, or for that matter, with the parents.

Not being able to see, or in some cases, even talk to the hospitalized child, coupled with the difficulty most parents experience communicating news about the child to the healthy siblings, commonly results in the children at home attempting to adjust to a situation without the benefit of adequate information. Often this lack of communication between siblings continues once the child with cancer is home. Turk (1964) described this pattern of diminished communication spreading to other aspects of family life as a "web of silence." This decrease in interaction may result in family members experiencing a sense of isolation.

A sibling intervention can provide much needed information about the cancer experience for the healthy members of the subsystem and perhaps open channels of communication between family members.

Hypothesis 1: Healthy siblings of children with cancer who participate in a "Sibling Saturday" will perceive an increase in family communication compared to perceptions before intervention.

Siblings of children with life threatening illnesses are often burdened with many painful emotions. Confused about what caused the illness, they sometimes experience guilt and shame by believing that somehow they are to blame. On the other hand, siblings at times feel guilty because they are glad that they escaped the disease. Because of the debilitating nature of cancer, they may also feel ashamed of their siblings' appearance (Sourkes, 1986).

Additionally, children may also feel anger at their parents, believing that somehow they allowed or perhaps even caused the cancer by not protecting their sibling. Anger may also be experienced by healthy siblings who, although understanding the fact that sick children require a great deal of parental attention, nevertheless have difficulty understanding why parents are not meeting the needs of the other children.

Anger and guilt may be expressed in various forms. One of the most common ways it is manifested in children is a depressed mood. Providing healthy siblings with information about cancer was expected to dispel many harmful misconceptions. In addition, the Sibling Day intervention would offer an opportunity for verbal and non-verbal expression of feelings.

Hypothesis 2: Healthy siblings of children with cancer who participate in a Sibling Day will experience a brighter mood than before intervention.

Children with cancer are likely to be experiencing the same sense of isolation as their healthy siblings. It was posited that participation in a Sibling Day would increase family communication. The healthy siblings were expected to talk more with their parents and their brother or sister with cancer. The conversations were expected to include a greater depth in expression of feelings and concerns. It was believed that this decrease in family isolation would be perceived by the children with cancer as well as their healthy siblings.

Hypothesis 3: Children with cancer whose healthy siblings participate in a Sibling Day intervention will perceive less family isolation than before intervention.

Children with cancer, as part of the grieving process that occurs with the diagnosis of life-threatening illness, are likely to be experiencing many of the same feelings of anger and guilt as their healthy siblings. A sibling day offers an opportunity for healthy siblings to explore some of these feelings from a family systems perspective. With an attitude of stressing that anything that is human is mentionable, and anything that is mentionable is manageable, it was hoped that there would be more freedom of expression of feelings among family members, including the sibling subsystem. Increased family communication was expected to result in a brighter mood not only for the healthy siblings, but for their brothers and sisters with cancer as well.

Hypothesis 4: Children with cancer whose healthy siblings participate in a sibling day intervention will experience a brighter mood than before intervention.

Methods

Subject Selection

Subjects for this study included children with cancer and their healthy siblings (See Appendix D). The subjects were referred by a physician, nurse, or social worker and participate in the study on a volunteer basis. Other families reponded to invitations mailed to their homes. A prerequisite for referral was the assumption that the patient's condition would remain fairly stable throughout the testing period of six weeks. Due to the informative nature of the intervention, the child and his sibling(s) were required to be aware of the diagnosis of cancer. At the time of the study, all of the families had a child receiving treatment for cancer at one of two outpatient oncology clinics in the southwest--one in a general acute care hospital, the other in a children's hospital one-hundred miles away. A small control group of 2 families was selected from families who were either unable to attend a sibling day or planned to participate in a later one. Participation in

the study was not a requirement of attending a Sibling Day. However, all of the attendees completed pretesting.

Instrumentation

Two instruments were chosen for the testing procedure. The first, the Kinetic Family Drawing Test-Revised, is an age independent measure that was completed by the children during the pre- and posttest phases of this study. The second, a demographic questionnaire, was completed by parents of the subjects during pretesting (See Appendix B).

Procedure

The investigator and clinic staff contacted parent(s) by mail, phone, or in person and explained the project's purpose of examining the sibling relationship when pediatric cancer is present. Sibling Day activities were described and an invitation for siblings to participate was extended. At the children's hospital, in an effort to have the largest group of siblings possible, an initial mailing asked parents to note a most convient day, time, and any obstacles, such as transportation, that might prevent their participation.

Pretesting. While some children and their siblings pretested during normal clinic visits, most pretesting occured on the mornings of the Sibling Day. In addition to parental consent, the investigator read a consent form to each child (See Appendix ?). Following age appropriate explanations and an opportunity for questions, older children signed the form and younger ones assented by making a mark. Each subject was tested individually in a comfortable room with only the investigator present.

Some children completed the drawing quickly in two or three minutes; others took as long as 15-20 minutes. When subjects had not spoken spontaneously about the meaning of the drawing during production, they were interviewed briefly at the conclusion of the testing period. The average drawing time, including the discussion with the child about the drawing, was 10 minutes.

Sibling Days. Over a three month period, three Sibling Days were given, one at a general acute care hospital and two at a children's hospital in a different city. Only siblings were invited; the children with cancer did not participate. A total of 13 siblings representing 9 families attended a Sibling Day. Each day consisted of the following activities:

1. Discussion and explanation of cancer lead by the clinic nurse or the investigator. Siblings were asked what they knew about cancer, the cause, treatment, prognosis, and other details. Discussant leaders provided information and made efforts to clarify misunderstandings.
2. A tour of the clinic, x-ray and the lab led by clinic staff.
3. A film concerning being a sibling of a child with a chronic illness or cancer: "My Brother is Sick" for children 3-10 years.and "Childhood Cancer: The Sibling's Perspective" for children 10 years and over.
4. Group sessions led by nurses with graduate training in family therapy. Remaining with their age grouping, children processed information from films and discussed personal issues. A snack was served at this time.
5. An expressive art session led by the investigator, a nurse with experience in art therapy with children.

Both age groups came back together for a group art project. On a large sheet of butcher's paper, the siblings used colored markers to outline their shoes. They were instructed to draw something about Sibling Day and write their names inside the shoe outlines. They could, of course, draw more than one shoe. They were further encouraged to write messages for their brothers or sisters to read, for the giant posters were displayed in the clinics the following week.

Two weeks following the "Sibling Saturday" intervention, testing was repeated on siblings and children with cancer following the same pretest procedure outlined

above. Because the Sibling Day was expected to be a positive learning experience for participants, following an additional two week period, sibling subjects from the control group were invitied to participate in a similar "Sibling Saturday."

Two weeks later a portion of these siblings and children with cancer received another posttest. In order to obtain a follow-up score, at this time an additional posttest was given to a portion of the subjects in the experimental group.

The quasi-experimental design used in this study may be outlined as follows:

Experimental Group	O_1	X_1	O_2	O_3
Control Group	O_4	O_5	X_2	O_6

Data Analysis and Testing of Hypotheses

Data from the KFD-R was initially gathered on an individual form to present a profile for each subject. Subscales in the areas of communication and emotional tone were recorded using a preset interpretation form (Spinetta et al, 1981). A second form combined data from subjects from the same family. Judgment of acceptance of hypotheses 1 and 3 was based on a statistically significant decrease in scores (reflecting an increase in family communication) on items K, L, N, O, P, Q, R, and S from first testing to second. Judgment of acceptance of hypotheses 2 and 4 was based on a statistically significant decrease in scores (reflecting a brightening of mood) on items D,F,G,H,I, and J from first testing to second. Scores on posttest 2 for the experimental group served to evaluate the longer term effect of the sibling intervention.

Results

Individual scores varied considerably from pretest,posttest, and second posttest.in those families participating in the one-time intervention as well as those who had not. As much as a 16 point difference was noted between a series of individual scores. In some cases scores increased, others decreased, others increased and decreased or

decreased and increased. Scores exhibited the same fluctuation when subjects from the same family were grouped and compared (See Appendixes D and E).

Due to the small sample size, no pattern could be determined. Because many of the subjects were under the age of 6, the choice of the KFD-R was probably unwise. Additionally, the tool is sensitive to how the subject feels at a particular moment in time, which--judging from the wide range of scores--may not have been useful in a study of a relatively short duration. Much rich material was obtained from the subjects drawings and discussions, however. While findings confirmed the variety of effects of childhood cancer on siblings recorded in the literature, findings clearly present evidence of the effects of current social changes in America as well.

APPENDIX J

PRESS RELEASE

FOR RELEASE: At will

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SIBLING STUDY CONFIRMS REPORTS THAT BROTHERS AND SISTERS OF CHILDREN WITH CANCER ARE OFTEN THE "FORGOTTEN ONES"

Research on siblings of children with cancer suggests that healthy siblings may experience more stress than any other member of the family. A recent sibling study through the Department of Family Relations and Child Development at Oklahoma State University, Stillwater, OK, supports these earlier findings. "Sibling Day" programs were held at hospitals in Oklahoma City and Tulsa to help siblings cope with the stress of having a brother or sister with cancer.

Because parents must divide their time between hospital and home, siblings are often left with a friend, relative, or sometimes alone. Although an increasing number of hospitals recognize the benefits of sibling visitation, many children with cancer receive specialized treatment in hospitals or clinics a great distance from home. This may result in the healthy siblings having very little contact with their brother or sister, or for that matter, with their parents.

Siblings of children with life-threatening illnesses are sometimes burdened with painful emotions. Confused about what caused the illness, they sometimes experience guilt and shame by believing that somehow they are to blame. On the other hand, siblings at times feel guilty because they are glad that they escaped the disease. Because of the debilitating nature of cancer, the may also feel ashamed of their brother or sister's appearance.

Some children may feel angry with their parents, believing that somehow parents allowed or perhaps even caused the cancer by not protecting their brother or sister. Anger may also be experienced by healthy siblings who, although understanding the fact that sick children require a great deal of parental attention, nevertheless have difficulty understanding why parents are not meeting the needs of the other children.

As part of the research study, siblings were asked to complete drawings of "everyone in your family doing something." Drawings indicated that some of the siblings feel isolated, neglected, sad, jealous, guilty, or angry. Children were asked to talk about their drawings, opening the door to discussions about some of these painful feelings. Other drawings revealed positive feelings between family members. Parents and children were doing things together, indicating that communication is "open" between members, a factor thought to be important for families attempting to adjust to having a child with cancer.

The "Sibling Day" programs provided an opportunity for siblings to tour the clinic where their brothers and sisters receive treatment and to learn more about childhood cancer through films and discussions. Perhaps, best of all, by meeting other children who shared similar feelings and concerns, these brothers and sisters of children with cancer learned that they are not alone.

VITA

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Candidate for the Degree of

Master of Science

Thesis: ALTERING MOOD IN CHILDREN WITH CANCER THROUGH INTERVENTION WITH THEIR HEALTHY SIBLINGS

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Personal Data: Born in Washington, DC, November 1, 1943, the daughter of Kenneth J. and Helen V. Holt. Married Michael W. Rollins, January 22, 1966. Four children: William L.-10/22/66; Katherine S.-9/16/68; Christine E.-1/28/70; and David M.-1/10/72.

Education: Graduated from Washington Hospital Center School of Nursing, Washington, DC in June, 1964; received Bachelor of Fine Arts in Art from University of Tulsa in May, 1980; completed requirements for the Master of Science degree at Oklahoma State University in May, 1989.

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