Childhood Cancer: Siblings Draw and Tell

Judy A. Rollins

There is a growing awareness among health care professionals that the psychosocial needs of siblings of children with cancer are less adequately met 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, 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 and reflect current social changes.

"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). While this is an old definition, it is one that even 30 years later frequently serves as the basis for initial emotional responses to the word "cancer." 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. Is it any wonder that news of such a disease would be sufficient cause for crisis in the family system?

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 that families must deal with on a daily basis.

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; Spinetta, 1981). At the time of diagnosis, probably all siblings feel left out to some degree. Family, friends, and 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 the ill sibling. Some of these changes result from the demands of the disease while others 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 their ill 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). Siblings are no longer able to compete, at least temporarily. Furthermore, when feelings of love and positive caring among siblings 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 these losses even more in a two-child family, the most prevalent size in America today.

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, or an alcoholic parent all have the potential to produce equal and in some cases greater levels of stress than disease-related stressors. Because siblings may react to nondisease-related stressors with similar behavior or adjustment problems, it may be inaccurately assumed that their difficulties are all a result of having a brother or sister with

JUDY A. ROLLINS, MS, RN, is a contributing editor for *Pediatric Nursing*, Pitman, NJ, and a consultant in Washington, DC.

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Table 1. Obtaining a Kinetic Family Drawing

1. Give the following instructions: "Draw everyone in your family doing something. Try to draw whole people, not cartoons or stick people. Remember, make everyone doing something."
2. Comment on notetaking: "I will be making some simple notes while you are drawing. We will talk about your drawing and my notes when you are finished."
3. Note, who was drawn first? Last? Was there any hesitation? Heavy pressure applied? Was heavy pressure used with all family members, or just certain ones? Also note any comments the child makes while drawing.
4. Wait for an indication that the child has finished drawing. Children will usually announce when the drawing is complete. If no announcement is made, ask, "Are you finished?"
5. First look at the drawing for the omission of family members. If someone is missing, ask, "Is this everyone in your family?"
6. Ask child to explain what each family member is doing. Add this data to notes.
7. Encourage child to tell as much as possible about the drawing, using the opportunity to explore concerns, if appropriate.
8. Thank the child and offer praise for a job well done.

Note: Older children and adolescents may be more comfortable drawing alone. They may be instructed to write thoughts and comments directly on the drawing. Follow with the interview after the child has finished drawing.
(Adapted from Spinetta, McLaren, Fox, & Sparta, 1981; Rollins, in press.)

Table 2. Overview of KFD-R Scoring System (Negatively valenced)

Categories		Points
A.	Incompleteness of body	0-2
B.	Frequency of missing body parts	0-2
C.	Cross-outs	0-2
D.	Conditions of nature (weather)	0-2
E.	Subject portrayal	0-1
F.	Use of color	0-2
G.	Use of space on paper	0-2
H.	Developmental level	0-1
I.	Use of stick figures	0-1
J.	Facial completeness of subject	0-2
K.	Compartmentalization	0-2
L.	Barriers	0-2
M.	Figure size	0-2
N.	Used front-back of paper	0-2
O.	Exclusions	0-2
P.	Body position of patient	0-2
Q.	Body position of mother	0-2
R.	Facial position of patient	0-2
S.	Facial position of mother	0-2
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

(Adapted from Spinetta, McLaren, Fox, & Sparta, 1981)

cancer. A comprehensive approach to sibling intervention considers nondisease as well as diseased-related stressors.

This study attempted to gain some understanding of siblings of children with cancer through analyzing drawings of their families. It was expected that for some children, cancer will be a predominant theme; for others, however, nondisease-related stressors may be more important. Also, some families would be seen as healthy and well-functioning regardless of the diagnosis of 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. 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. Because drawing is typically viewed by children as a nonthreatening and enjoyable activity, one of the instruments selected for the study was the Kinetic Family Drawing Test-Revised (Spinetta, McLaren, Fox, & Sparta, 1981). Furthermore, children, particularly young ones, usually express themselves more naturally and spontaneously through actions rather than through words (DiLeo, 1983). It is assumed that the figure drawn is a unique expression of a child's experiences and preferences. Over time, a series of drawings 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). Used with interviews and other therapeutic techniques, the Kinetic Family Drawing (KFD) provides information about how children perceive themselves in their family setting. Burns and Kaufman (1972) found kinetic (action) drawings more informative than those obtained from the traditional akinetic instructions. The addition of movement helps mobilize a child's feelings not only as related to self-concept, but also in the area of interpersonal relations. 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 families. Useful with adults and children 6 years and older, the KFD-R procedure precludes chance and/or the problematic tendency to overinterpret drawings, when administered and scored by a trained professional.

Procedure

After obtaining consent from children and parents, the investigator administered the KFD-R in standard fashion, although felt tip markers were used rather than colored pencils. Children were given a sheet of plain white 8½ by 11 inch paper and a package of 10 colored markers. (For instructions on obtaining a kinetic family drawing, see Table 1.) Although all the children

Table 3. Scanning a Kinetic Family Drawing
(Burns, 1982)

Drawings by children under 6 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?

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 Table 2). For younger children, drawings may be "scanned" to elicit possible information for interpretation (see Table 3).

Results

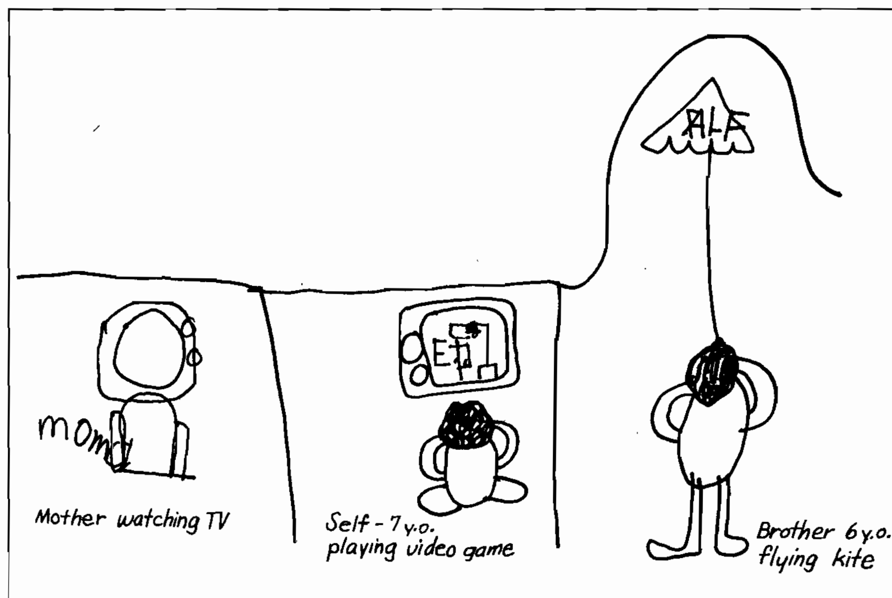
Given the low sample sizes, a case study approach to the data was chosen. Of interest were the findings indicating nondisease-related stressors. Certainly all children's responses were individualized and unique. Although many cases were interesting, only three are presented for detailed description to reflect a 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, age 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. Because Mrs. Green works full time outside the home, Timmy's grandmother usually brings him to the clinic. Scott almost always accompanies them.*

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).

Under the KFD-R scoring system, Scott's drawing received 10 out of a possible 16 points on the subscale "Communication." An important feature to note is that everyone is in a compartment separated by lines, comprising barriers among 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. 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 1 (black) of 10 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. Scott seemed to be somewhat depressed, yet unable to talk about 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."

Figure 1. Seven-year-old Scott Drew Barriers Between Members of His Family



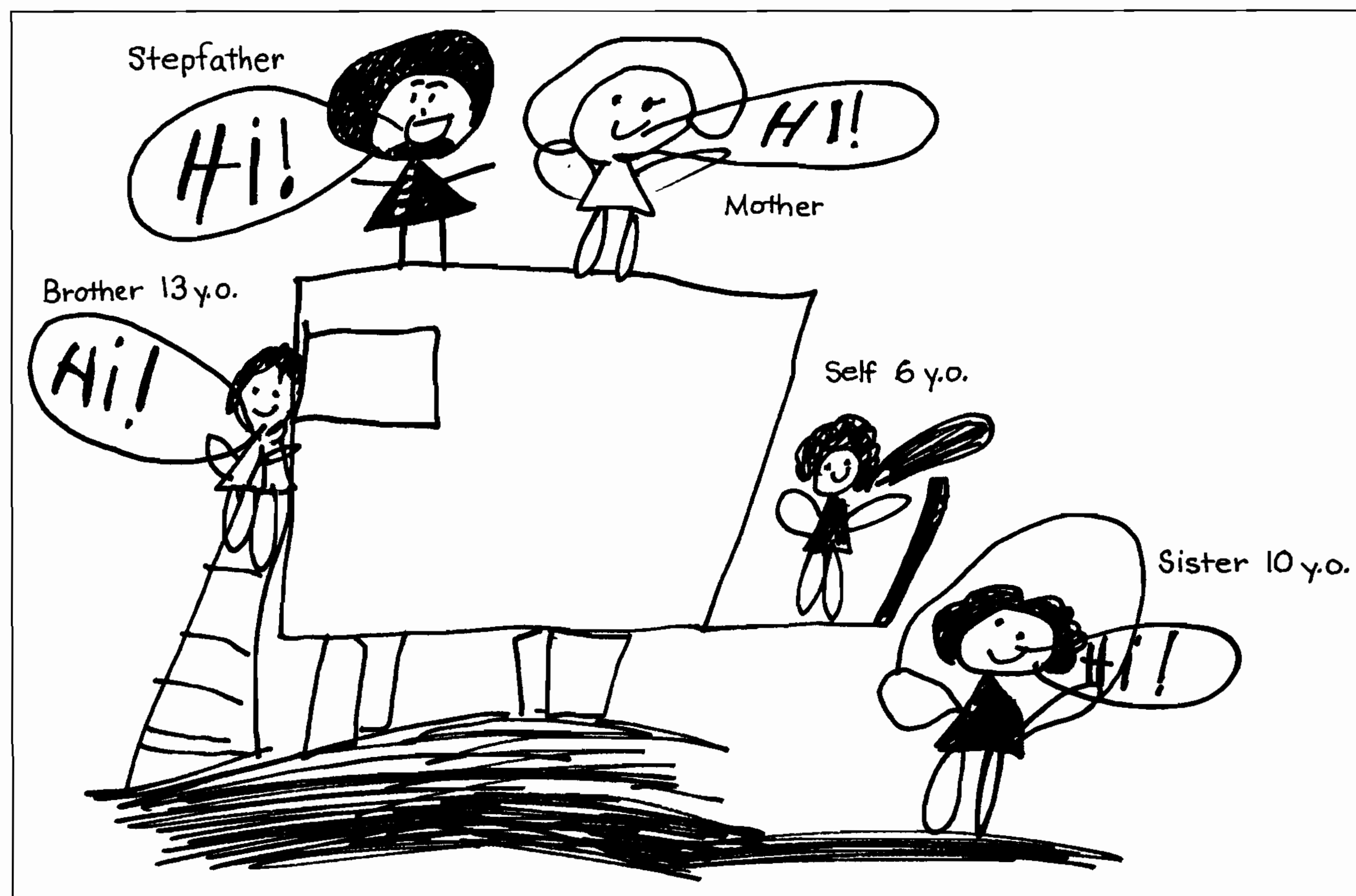
Analyzing the drawing, it appears that Scott is feeling very little communication among family members. Timmy seems to be the biggest and most important member of the family (Timmy portrayed himself the same way in his family drawings). Mother may be perceived as unavailable for Scott and perhaps Timmy, too. While Scott talked very little about the meaning of his drawing, he produced two similar kinetic family drawings over a 6-week period, all scoring within the same range. Timmy's drawings, though more adaptive than Scott's, also indicate a lack of communication among 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 four 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. Jennifer is an offspring of her second marriage. Sam was diagnosed with acute lymphocytic leukemia 3 years ago during the Johnson's 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 appears very supportive. He, too, seems to enjoy family life. In his spare time, he built a backyard playhouse, the subject of Sally's first family drawing (see Figure 2).*

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 was 6 points. Additionally, in her drawing she used a stickfigure to portray her stepfather, and omitted the nose on her face. Her combined score totaled 10, representing a fairly adaptive drawing.

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 produced their first drawings, Sam was at the

Figure 2. Six-year-old Sally Drew Her Family "Playing in the Backyard in the Clubhouse Daddy Built"



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 it's 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 sigh 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.

In a later drawing, Sally again omitted Jennifer. Ten-year-old Karen also omitted Jennifer from one of her drawings. This family has experienced a great number of significant changes over the past 3 years, any one in itself a sufficient cause of stress. Within 1 year, the family added two new members (stepfather and baby sister) and is faced with the threat of losing a member (Sam). Apparently, some family members are still struggling to adapt to the many changes in the family. 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 changes 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 since childhood cancer was accompanied by other significant life events.

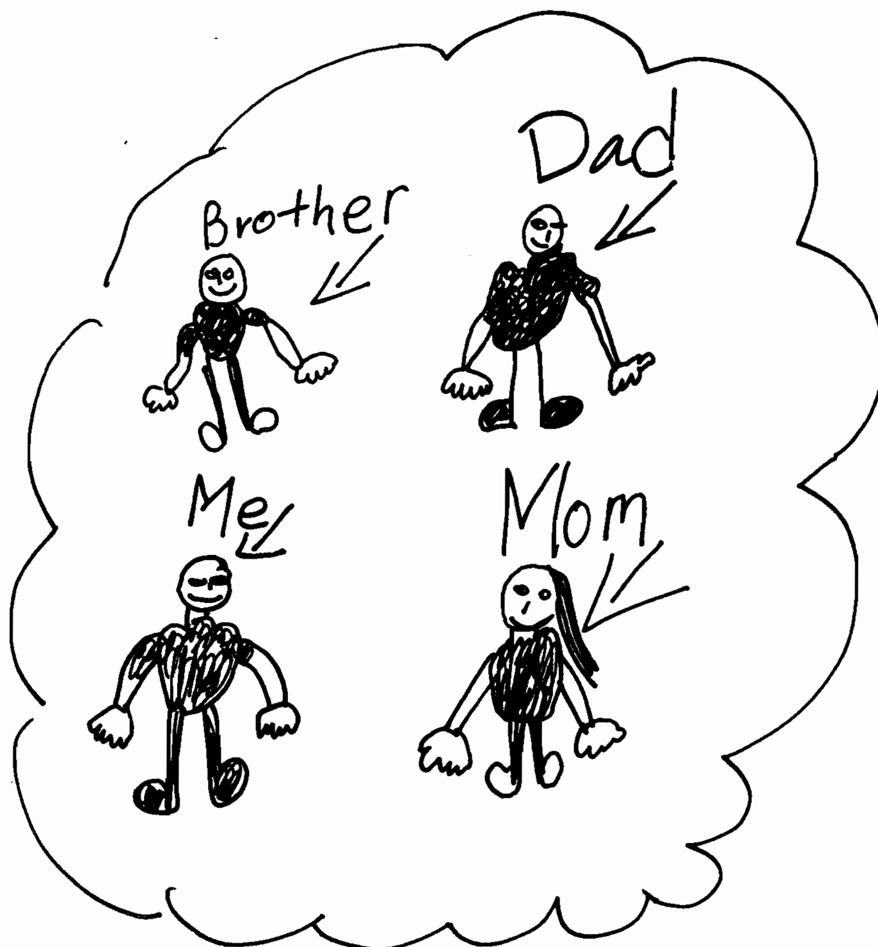
Case study 3: The Stevens Family. *This was a second marriage for both Mr. and Mrs. Stevens. Mrs. Stevens is employed while Mr. Stevens attends a vocational training school. When they married 5 years ago they each brought to the union 4-year-old sons, Darryl and Donald. Now 9 years old, Darryl — Mr. Steven's natural son — had been diagnosed with osteosarcoma of the right arm 5 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 (see Figure 3).*

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 totaled 3, indicating an adaptive drawing.

Additional information, however, was obtained during the group discussion segment of sibling day. 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 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. Of interest is 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 to lose your arm. 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."

Figure 3. Nine-year-old Donald Produced This Drawing of His Family "Just Standing There"



Discussion

Siblings' drawings and follow-up discussions disclose not only issues regarding cancer, but additional concerns unrelated to the disease. Many nondisease-related stressors are a result of 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).

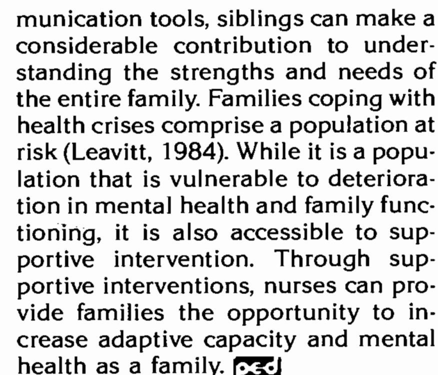
Some of these nondisease-related stressors seemed evident in many of the drawings in this study. For example, other children from single-parent families drew pictures similar to Scott's, with barriers between family members. Drawings of younger children from single-parent or divorced parents indicated 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 even 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 unavailable 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 help validate 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).

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 8 or 10 years (Bank & Kahn, 1982). Drawings from high-access siblings in the study, such as, Scott and Timmy, could 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. Drawings that reflect an intense emotional bond can be verified by discussion and observation.

If the trend to have only two children spaced 2 to 3 years apart continues, we may soon be dealing almost exclusively with a population of siblings defined as high-access. Nurses 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. Nurses may somehow be able to take advantage of this bond and use it in a positive way.

In closing, a plea is issued for 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, nurses need a basic knowledge of the developmental stages of children's drawing; children draw differently as they develop. What may be a maladaptive drawing for a 10-year-old might be perfectly appropriate for a child of 5. Second, clear, specific guidelines should be established prior to the evaluation of any drawings. Other methods are available for interpreting the KFD, such as a grid to help focus attention to particular areas. O'Brien and Patton (1974) have developed a computer program to score KFDs. Third, children's drawings should always be assessed over time, since little replicability is seen in only one or two drawings from any child. Fourth, with any drawing, nurses need to be adequately prepared to analyze drawings and must resist the urge to overinterpret. Children should be asked to validate what the interpreter thinks the picture represents, or at least 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 nondisease 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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