Behavior Changes Exhibited by Siblings of Pediatric Oncology Patients: A Comparison Between Maternal and Sibling Descriptions

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The purpose of this study was to identify the coping strategies used by the well siblings of pediatric oncology patients as identified by both the mother and the well siblings. The findings of this research study showed that both mothers and the well siblings were able to identify behavioral changes (95.2% of the mothers and 85.7% of the well siblings identified behavior changes). Behavior changes identified by both the siblings and mothers included being more sensitive to the needs of others, being more thoughtful, playing with friends, fighting, trouble sleeping, and complaints of headaches. Nurses can conduct thorough assessments of sibling behavior changes when a child family member has been diagnosed with cancer. From these assessments, nurses can provide care to assist the entire family during the ill child's treatment.
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RESEARCH FINDINGS from several studies indicate that siblings of pediatric oncology patients exhibit stress responses and related coping strategies[1-6] during the cancer experience. The siblings' efforts to cope may be successful or unsuccessful in different situations or settings. Unsuccessful efforts may exacerbate the stress of the situation and result in short-term or long-term difficulties for the well sibling or the family. Research about the coping strategies used by well siblings could provide nurses with information to use in promoting successful coping.[7]

Studies describing the coping strategies used by siblings of pediatric oncology patients do not typically include reports by both the mother and the healthy sibling. The purpose of this research was threefold: (1) to document the coping strategies that the well siblings of pediatric oncology patients report, (2) to document the coping strategies used by the well siblings as reported by their mothers, and (3) to compare descriptively the mothers' report of the coping strategies of the well siblings with the siblings' reports.

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Literature Review

Coping is identified as a process in which observations and assessments are based on the individual's actual actions; changes in coping behaviors can occur as a stressful situation arises.[8] Lazarus and Folkman[8] defined coping as "constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Appraisal and coping strategies affect the outcomes, which can be either adaptive or maladaptive. Outcomes are complex, interrelated, and can differ in each individual; what may be an adaptive outcome for one individual may be maladaptive for another.

Adaptive or successful coping methods can be both cognitive and behavioral and are

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either problem-focused or emotion-focused.[8] Problem-focused coping strategies are similar to problem solving. Such strategies focus on helping the individual to define the problem, generate solutions, and choose the best solution to the problem. Emotion-focused coping efforts are directed at regulating the emotional reaction to the problem. This includes strategies such as avoidance, minimization, distancing, selective attention, positive comparisons, and eliciting positive values from negative events.[8] Conversely, maladaptive or unsuccessful coping occurs when an individual is unable to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person. Maladaptive coping includes denial, regression, and excessive aggression.[8]

Families of pediatric oncology patients experience stress from the time of diagnosis throughout the illness. Whether the patient is in remission or has died, the family is responding to the stressors of returning to normal routines such as returning to work, school, and group activities. The relationship between Lazarus and Folkmans' theoretical framework and the well siblings of pediatric oncology patients can be described as follows: the well sibling comes in contact with the stressor of his brother or sister being diagnosed with cancer. The well sibling then appraises the stressor as either a loss, threat, harm, or challenge. Once the well sibling fully appraises the stressor, he or she selects and implements coping strategies. These coping strategies manifest themselves as either adaptive or maladaptive.

Within the last decade, researchers have explored the effects of pediatric cancer on well siblings. Walker[6] defined siblings as persons who share a common bond in relation to background and outlook. The siblings also share their parents' love, time, and interest. When a child is diagnosed with cancer, siblings can feel that they have lost their parents' time and interest as their parents' attention is focused on the ill child. Siblings can also experience a feeling of loss when their parents are away at the hospital and their roles and routines are changed.[9]

Iles[3] conducted a pilot study to determine what healthy siblings of pediatric oncology patients perceive their experiences to be during the illness. The siblings described themselves as scared, sad, worried, jealous, angry, and hopeful. They wanted to be kept informed and they also wanted their parents to make them feel special, too.[3] Kramer[5] studied healthy siblings' perceptions of living with a brother or sister with cancer. The siblings experienced three major stressors. The first stressor was the emotional realignment that occurred when the parents became preoccupied with the ill child. The well siblings felt the parents favored the child with cancer and that, as a result, they did not receive enough attention. This, in turn, resulted in them feeling anger, frustration, guilt, and increased sibling rivalry. The second stressor was separation from the rest of the family. The siblings reported the following: (1) adequate information was not provided regarding the ill child, (2) a decrease in family involvement occurred, and (3) there was insufficient social support. Feelings of sadness, loneliness, confusion, anxiety, and isolation were also described. The third source of stress was the cancer child's regimen. The siblings witnessed the child undergoing physical and personality changes, along with anxiety and pain. The siblings responded with feelings of guilt, anger, fear, anxiety, embarrassment, and frustration. In addition, some positive and adaptive responses of the healthy siblings emerged. These included an increased sensitivity and empathy toward the ill child and the parents, an increase in maturity, and an increase in closeness of the family unit.

Koch-Hattem[4] interviewed 33 well siblings of pediatric oncology patients. The study purpose was to identify how the well siblings perceived the changes in their families. The interviews contained 30 forced-choice questions concerning changes experienced by the siblings after a diagnosis of cancer in a brother or sister. Siblings reported being bothered, sad, and scared more frequently after the patient was diagnosed with cancer. Most siblings expressed emotions such as anger, crying, or either wanting to be alone or seeking others' company when they were

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sad, bothered, or scared. The siblings' most frequent behavioral responses to anxiety and depression were difficulty in falling asleep, fear of becoming ill, worrying about self when ill, a lack of desire to go to school or to study, and an increased frequency of being ill.

Walker[10] incorporated the parents and the siblings in identifying the siblings' behavioral and cognitive coping strategies. Data were collected from 15 families for a total of 26 siblings using both open-ended interviews and questionnaires designed for both the parents and the siblings. A parental interview was conducted to identify stressful issues of the family and to discuss the siblings. The siblings participated in a 1-hour interview, which included puppet play and drawings. The major stressors, as identified by the siblings, and the responses to the stressors were included. Parental identification of sibling stressors and coping revealed that 69% of the siblings displayed one or more types of stress response. The most common stressors were affective stress responses, particularly verbal. These included swearing, arguing, irritability, and disrespect to adults. Emotional responses included profound sadness and lability. Five parents could not identify any coping strategies in the siblings.

Petersen[11] reviewed eight research studies, each using different theoretical backgrounds and methodologies which examined children's coping in response to discrete, stressful, medical procedures. The studies all conceptualized children's coping in an active versus avoidance scale. Each study also identified that the active end of the scale was associated with more adaptive responses. These included children seeking information and asking questions. The avoidance end of the scale was associated with more maladaptive responses, which included denial, displacement, and projection.

Ryan-Wenger[12] studied 242 healthy midwestern schoolage students from 8 to 12 years old using the Schoolagers' Coping Strategies Inventory (SCSI). The SCSI is a self-report instrument that measures the frequency and effectiveness of children's stress-coping strategies. The study showed that 8- to 12-year-old children are capable of appraising the frequency and effectiveness of their own coping strategies. Interestingly, the 8- and 9-year olds had a higher frequency score than the 10-, 11-, and 12-year olds. This difference suggests younger children use a variety of coping strategies whereas the older children rely on fewer strategies which they know work for them. The effectiveness of coping was not different between the age groups which indicates that children are able to use their coping strategies and cope well with stressors. This study suggests that children's coping strategies are changing as they procede through each developmental stage.

Sorensen[13] examined 32 well children aged 8- to 11-years. Each child responded to an interview sentence completion list and completed a daily semistructured journal over a period of 6 weeks. The study found that the children responded differently to hypothetical stressors (sentence completion list) and how they actually responded (semistructured daily journals). Coping responses of submission/endurance were reported twice as often in the journals than in the sentence completion exercises. Also, children were less likely to use avoidance/flight in actual life situations. Other categories showing a high response rate were emotional sensory and problem solving. The most common coping support source identified by the children was their mother. Girls were more likely to identify emotional sensory and emotional expression whereas boys were more likely to use physical aggression.

In summary, the research has shown that healthy children of diverse age groups are able to report and articulate a variety of coping strategies that they use. Research in the past has focused on the coping strategies of the parents and the child with cancer. It has been only recently that research has considered well siblings while the child with cancer is still alive. The siblings of cancer patients have most commonly identified feelings of loneliness, sadness, anxiety, and depression during the illness phase. The siblings have also identified a change in their daily routine with more responsibility placed on them. Finally, previous research findings have indi-

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cated that mothers were not always aware of the coping strategies of the well siblings or were in disagreement with what the siblings identified as their coping strategies.

Methodology

Sample

A nonprobability purposive sample of mothers and siblings was selected from a computerized census list of pediatric oncology patients who were currently undergoing treatment for a malignancy. The setting of the study was northern New Jersey which is primarily a metropolitan suburban area. The sample was selected from clients of the Valerie Fund Children's Center at Overlook Hospital in Summit, NJ. Inclusion criteria for the well siblings were as follows: siblings had to be 9 to 18 years of age, have a brother or sister on active treatment for a malignancy for at least 3 months, and live with the ill sibling and mother. Inclusion criteria for the mothers were that they had to be 19 years old or older, the primary caregiver to the well sibling and the sibling with cancer, and live in the same household as the healthy and ill siblings. Thirty-four families were eligible for participation in the study. Each family was invited to participate in the study by mail. Seventeen families completed the study instruments and returned them by mail. The final sample consisted of 17 families with four of the mothers responding for two siblings each making a total of 17 mothers and 21 siblings.

Of the 17 families, the types of cancer manifested by the pediatric oncology patients were primarily leukemia, lymphoma, and brain tumors. At the time of diagnosis, the majority of the patients were between the ages of 11 and 14 years (29.4%). The type of treatment the child received varied between surgery (47.1%), radiation (52.4%), and bone marrow transplant (52.9%). All the children received chemotherapy as part of their treatment. When the children were hospitalized, the mother stayed with them 76.2% of the time, and in 28.8% of the time the mother or the father stayed (Table 1).

TABLE 1.
Demographic Characteristics of the Pediatric Oncology Patients for the Sample (n = 17)

Characteristics	n	%
Current age (years)		
0-3	1	5.9
4-6	2	11.8
7-10	4	23.5
11-14	7	41.2
15-18	3	17.6
Age when diagnosed		
0-3	3	17.6
4-6	2	11.8
7-10	4	23.5
11-14	5	29.4
15-18	3	17.6
Surgery as treatment		
Yes	8	47.1
No	9	52.9
Radiation as treatment		
Yes	9	52.9
No	8	47.1
Chemotherapy as treatment		
Yes	17	100.0
Bone marrow transplant as treatment		
Yes	1	5.9
No	16	94.1

The mothers were between 33 and 48 years of age with 52.4% between 41 and 48 years of age. All families were white and 90.5% of the mothers were married. Eight (47.1%) mothers had 4-year college degrees; seven families (41.2%) had an annual income of $50,000 to $75,000; five (29.4%) had an annual income of $25,000 to $50,000; five (29.4%) had an annual income of $75,000 to $100,000; two (11.8%) had an annual income of $100,000 to $150,000; and two (11.8%) had an annual income of $150,000 and greater.

The 21 well siblings ranged in age from 9 years to 18 years; 5 siblings were between the ages of 9 and 10 years, 10 siblings were between the ages of 11 and 14 years, and 6 siblings were between the ages of 15 and 18 years. Eleven of 21 siblings were female and 10 were male.

Design

The well siblings and their mothers completed the study packets at home and returned them by mail. The study packet consisted of an introduction letter, a copy of an

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informed consent for the mother and each sibling participant, a demographic data form, a parent questionnaire for each well sibling between the ages of 9 and 18 years living in the house, a sibling questionnaire for each well sibling between the ages of 9 and 18 years living in the house, and a large preaddressed stamped envelope. Two weeks after the packet was mailed, mothers received a follow-up phone call to determine their desire to participate in the study and to answer questions. A time frame of 3 weeks was allowed for responses.

Instruments

The study questionaire was developed from Walker's open ended interview format.[10] The original questionaire was titled Parental Identification of Healthy Sibling Coping Strategies. The title was changed to enhance readability and was referred to as Parental Assessment of Sibling Coping Strategies (PASCS) (Fig 1). The PASCS contained 33 questions that elicited "yes"/"no" responses. These questions pertained to the healthy sibling's behavior or behavioral changes since the diagnosis of the sibling with cancer. Additional data collected included behavior changes with regard to their being new, not new, and the direction of change (increase or decrease). In addition to the 33 "yes"/"no" questions in the PASCS, six open-ended questions were included for the mother to respond to in a sentence format. These included the following: What do you think are this child's main ways of coping with stress?; Are there any special behaviors that he/she uses?; Is this child on any medications?; Does this child know of his/her sibling's cancer diagnosis?; What have you told him/her about the disease?; Any other complaints of things you have noticed to be different in this child since his/her sibling has been diagnosed with cancer? Figure 1 shows example items and the questionnaire format.

The instrument used to allow the well siblings to report on their own behavior changes was also based on a sibling sentence completion test developed by Walker.[10] The Sibling Coping Ability Assessment (SCAA) was modified to eliminate the interview format originally included in Walker's study. Items were reworded to increase response rates, decrease set responses, and to appeal to children in terms of readability and understandability. Additional items were derived from a review of the current research literature concerning sibling responses to children with cancer. The SCAA was also modified for the purpose of scoring to allow for ordinal level data. It also included space for the healthy sibling to record his/her age and sex.

The modified SCAA contained 20 questions. The sibling was asked to read each statement on the SCAA carefully and circle the answer that best matched the way that he/she felt regarding the brother's or sister's receiving treatment for cancer. Scores for the SCAA were percentages based on how many siblings responded "yes," how many responded "no," and how many responded "maybe" (Fig 2).

The modified PASCS and the SCAA were analyzed by four master's prepared clinical nurse specialists with an expertise in the field of pediatric oncology. The purpose of this analysis was to determine if the two instruments were comprehensive, efficient, objective, easy to read, and had easy to understand directions. Two of four practitioners felt that the questionnaires contained clear directions, easy readability, and contained understandable questions. The other two practitioners thought that the directions on the PASCS were awkward. The directions were revised to include a completed sample item to help increase clarity.

Analysis

Demographic data were analyzed using measures of central tendencies. Demographic data obtained from the mother included age, marital status, ethnic background, level of education, and income level. Data analysis for the objectives involved measures of central tendencies. The Statistical Package for the Social Sciences was used to analyze the data.

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Parental Identification of Healthy Sibling Coping Strategies

Instructions: Please complete the following questions as honestly as you can. The following questions will ask you to recall information about one of your children during the time that you had a child receiving treatment for cancer.

It is very important that you identify the child that your answers are related to by age and sex. Remember that each question is about the healthy sibling, not the child with cancer.

Healthy Sibling's present age: _____ Healthy Sibling's sex: _____

For example: Suppose your ten year old daughter has recently started to skip meals or complain of not being hungry. You would complete this survey as follows:

	yes	*no*	*new?*	*not new*	*change* ↑ *or* ↓
1. change in appetite?	X		X		↓

Since your child has been diagnosed and undergoing treatment for cancer, has this healthy sibling had or experienced any:

	yes	*no*	*new?*	*not new*	*change* ↑ *or* ↓
1. change in appetite?					
2. change in weight?					
3. trouble getting to sleep at night?					
4. restlessness while sleeping?					
5. difficulty waking up?					
6. complaints of being tired?					
7. complaints of headaches?					
8. complaints of stomachaches?					
9. complaints of bone/muscle aches?					
10. trouble wetting the bed?					
11. general complaints of not feeling well?					
12. changes in friends?					
13. changes in playing with friends?					
14. change in activities?					
15. change in ability to have fun?					
16. seem less interested in being with others?					
17. more quiet than usual?					
18. more sensitive to needs of others?					

FIGURE 1. Parental Identification of Healthy Sibling Coping Strategies (continued next page).

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19. any changes in the following behaviors?:					
irritability					
mood swings					
aggressiveness					
arguing					
sadness					
talkative					
disrespectful					
emotional lability					
fighting					
agitated or nervous					
acting out					
attention-seeking					
more thoughtful					
20. any previous health care needs?					
21. any previous mental health needs?					

22. What do you think are this child's main ways of coping with stress?

    Are there any special behaviors that he/she uses?

23. Is this child on any medication?

24. Does this child know of his/her sibling's cancer diagnosis?

25. What have you told him/her about the disease?

26. Any other complaints or things you have noticed to be different in this child since his/her sibling has been diagnosed with cancer?

FIGURE 1. (cont'd.) Parental Identification of Healthy Sibling Coping Strategies (Used and modified with permission from Dr Carolyn Walker.)

Results

Fifty-one and one tenths percent of the mothers reported changes in the well sibling under the PASCS item of "more sensitive to needs of others." In 42.9% of these this was a new behavior. One third of the mothers reported changes in the well sibling with regard to the "presence of headaches" and "change

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SIBLING COPING ABILITY ASSESSMENT

This assessment is intended for use by a child (sibling) ages 9-18 who has had or is having a brother or sister undergo treatment for cancer. Please have your child read each statement carefully and CIRCLE the best answer that matches the way that they felt when their brother or sister was receiving treatment for their cancer.

Circle '1' for yes, you agree with the statement.
Circle '2' for maybe, you can't decide either way about the statement.
Circle '3' for no, you disagree with the statement.

	YES	MAYBE	NO
1. It is easy for me to fall asleep at night.	1	2	3
2. I often feel tired.	1	2	3
3. My appetite is always good.	1	2	3
4. I sometimes have a restless night's sleep.	1	2	3
5. When I have a problem I talk to someone about it.	1	2	3
6. Sometimes I cry for no particular reason.	1	2	3
7. I enjoy playing with my friends.	1	2	3
8. Sometimes when I am alone, I pray.	1	2	3
9. I worry about my brother's (or sister's) sickness all the time.	1	2	3
10. I find that I get into fights a lot.	1	2	3
11. I like doing things for my brother (or sister).	1	2	3
12. I like to be alone a majority of the time.	1	2	3
13. Usually I can talk to my mother.	1	2	3
14. I often feel afraid.	1	2	3
15. I sometimes think about running away or hiding.	1	2	3
16. I help out with chores around the house.	1	2	3
17. I often get stomachaches and headaches when I am at school.	1	2	3
18. I often bug my mom.	1	2	3
19. I have a person that I consider my best friend.	1	2	3
20. I sometimes yell at my mom and other family members.	1	2	3

FIGURE 2. Sibling Coping Ability Assessment.

in mood swings." Six mothers reported that the well sibling showed behaviors such as "more quiet than usual," "change in aggressiveness," "more talkative," "disrespectful," "attention seeking," and "more thoughtful." More than 70% of the mothers reported no changes in the well siblings' behavior with regard to 28 of the behaviors listed in the PASCS. Five of the mothers reported the following behaviors as new: "complaints of headaches," "more quiet than usual," "change in mood swings," "change in aggressiveness," "more talkative," "disrespectful," and "more thoughtful" (Table 2).

More than 50% of the 21 well siblings reported behaviors on the SCAA such as "appetite is good," "cries for no reason," "enjoys playing with friends," "gets into fights a lot," "likes to be alone when upset," "thinking about running away and hiding," "gets headaches at school," and "has a best friend" (Table 3). More than 61% of the well siblings reported that when they have a problem they talk to someone. None of the well siblings reported being "often afraid."

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TABLE 2.
Percentage Scores of the Individual Parental Assessment of Sibling Coping Strategies as Reported by the Mothers (n = 21)

	Yes		No		New		Not New		Change Increase		Change Decrease	
Variables	n	%	n	%	n	%	n	%	n	%	n	%
Change appetite	1	4.8	20	90.5	1	4.8	0	0	1	4.8	0	0
Change weight	2	9.5	19	90.5	1	4.8	0	0	2	9.5	0	0
Trouble sleeping	5	23.8	16	76.2	4	19.0	1	4.8	4	19.0	1	4.8
Restless while sleeping	4	19.0	17	81.0	3	14.3	1	4.8	3	14.3	1	4.8
Difficulty waking up	1	4.8	20	95.2	1	4.8	0	0	1	4.8	0	0
Complaints of tiredness	4	19.0	17	81.0	4	19.0	0	0	4	19.0	0	0
Complaints of headaches	7	33.3	14	66.7	5	23.8	2	9.5	7	33.3	0	0
Complaints of stomach-aches	2	9.5	18	85.7	1	4.8	1	4.8	2	9.5	0	0
Bone/muscle aches	4	19.0	17	81.0	2	9.5	2	9.5	3	14.3	0	0
Wetting the bed	0	0	21	100.	0	0	0	0	0	0	0	0
Complaints of not feeling well	1	4.8	20	95.2	1	4.8	0	0	1	4.8	0	0
Change in friends	1	4.8	20	95.2	1	4.8	0	0	1	4.8	0	0
Change in playing with friends	0	0	21	100.	0	0	0	0	0	0	0	0
Change in activities	0	0	21	100.	0	0	0	0	0	0	0	0
Change ability to have fun	0	0	21	100.	0	0	0	0	0	0	0	0
Less interested in others	2	9.5	19	90.5	2	9.5	0	0	1	4.8	1	4.8
More quiet than usual	6	28.6	15	71.4	5	23.8	0	0	4	19.0	1	4.8
More sensitive to others	12	57.1	9	42.9	9	42.9	3	14.3	10	47.6	2	9.5
Change in irritability	5	23.8	16	76.2	4	19.0	0	0	4	19.0	0	0
Change in mood swings	7	33.3	14	66.7	5	23.8	2	9.5	6	28.6	0	0
Change in aggressiveness	6	28.6	15	71.4	5	23.8	1	4.8	4	19.0	1	4.8
Change in arguing	4	19.0	17	81.0	3	14.3	1	4.8	3	14.3	1	4.8
Change in sadness	4	19.0	17	81.0	4	19.0	0	0	3	14.3	1	4.8
More talkative	6	28.6	15	71.4	5	23.8	1	4.8	5	23.8	1	4.8
Disrespectful	6	28.6	15	71.4	5	23.8	1	4.8	6	28.6	0	0
Change emotional lability	3	14.3	18	85.7	2	9.5	2	9.5	2	9.5	1	4.8
Change fighting	3	14.3	18	85.7	3	14.3	0	0	2	9.5	1	4.8
Agitated or nervous	4	19.0	17	81.0	3	14.3	1	4.8	3	14.3	1	4.8
Acting out	3	14.3	18	85.7	2	9.5	1	4.8	2	9.5	1	4.8
Attention seeking	6	28.6	15	71.4	4	19.0	1	4.8	4	19.0	1	4.8
More thoughtful	6	28.6	14	66.7	6	28.6	1	4.8	2	28.6	1	4.8
Previous health care needs	1	4.8	20	95.2	1	4.8	0	0	1	4.8	0	0
Previous mental health needs	1	4.8	20	95.2	1	4.8	0	0	0	0	0	0

Handwritten Comments From Mothers

The PASCS allowed the mothers the opportunity to respond in sentence form when asked what they thought was their healthy child's main method of coping with stress. Mothers responded with "he seemed to ignore what was happening," "she refused to face the realities of the illness and distanced herself," "she more or less ignored as much of what was happening as much as possible," "she verbally struck out at the family by nagging and badgering," and "she pretended not to care about what was happening."

When asked if they noted anything to be different in the well child since his/her sibling had been diagnosed with cancer, mothers responded with "he developed a greater appreciation for the sibling, the family, life itself, and became more appreciative of God and his place in our lives," "she became more independent," "her school grades dropped dramatically and she did not work to her full potential," "she became terrified to sleep or

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TABLE 3.
Percentage of Scores for Individual Sibling Coping Ability Assessment Items as Reported by the Healthy Sibling (n = 21)

SCAA Items	Yes		No		Maybe	
	n	%	n	%	n	%
1. Easy to fall asleep at night	10	47.6	8	38.1	2	9.5
2. Often feels tired	9	42.9	5	23.8	6	28.6
3. Good appetite	17	81.0	2	9.5	1	4.8
4. Restless nights sleep	9	42.9	4	19.0	7	33.3
5. Talks about problems	5	23.8	13	61.9	2	9.5
6. Cries for no reason	13	61.9	5	23.8	2	9.5
7. Enjoys playing with friends	17	81.0	2	9.5	1	4.8
8. Prays when alone	6	28.6	7	33.3	7	33.3
9. Worries about sibling's sickness	4	19.0	10	47.6	6	28.6
10. Gets into fights a lot	15	71.4	4	19.0	1	4.8
11. Likes doing things for sick sibling	8	38.1	7	33.3	5	23.8
12. Likes to be alone when upset	12	57.1	6	28.6	2	9.5
13. Usually can talk to mother	9	42.9	9	42.9	2	9.5
14. Often feels afraid	13	61.9	0	0	7	33.3
15. Thinks about running away/hiding	17	81.0	2	9.5	1	4.8
16. Helps with chores	9	42.9	9	42.9	2	9.5
17. Gets stomachaches/headaches	14	66.7	3	14.3	3	14.3
18. Often bug my Mom	5	23.8	8	38.1	7	33.3
19. Has a best friend	16	76.2	1	4.8	3	4.3
20. Yells at Mom and family members	2	9.5	4	19.0	14	66.7

Of the 21 siblings who responded, 1 completed the questionnaire incorrectly. The percentages were calculated based on a sample of 21 because the mother completed a questionnaire for the sibling.

to be alone," and "he seemed less aware, tuned in, or responsive than the other children."

All 17 mothers reported that they informed the well child about his/her sibling's cancer diagnosis. The mothers also reported that they honestly informed the well sibling about the ill child's disease process.

Discussion of Findings

The findings of this research study indicate that both mothers and siblings were able to identify behavior changes exhibited by the siblings as measured by the PASCS and SCAA. Similarities and differences between maternal and sibling descriptions were evident in the study, but, overall, 95.2% of the mothers and 85.7% of the healthy siblings identified behavior changes. These behavior changes included being more sensitive to the needs of others, being more thoughtful, enjoying playing with friends, having a best friend, trouble sleeping, headaches, stomachaches, aggressiveness, fighting, disrespectfulness, mood swings, irritability, attention seeking behaviors, and thoughts of running away or hiding.

Some mothers identified changes in behaviors of well siblings while the ill child was undergoing treatment for a malignancy. It was reported that the well siblings exhibited a change in the following behaviors: being more sensitive, thoughtful, quiet, argumentative, agitated, and nervous; experienced mood swings, emotional lability, and headaches.

In addition, mothers responded in sentence format that the well siblings' main methods of coping were to ignore or distance themselves from the family crisis. Although the well siblings appeared to ignore the situation, the mothers reported them to be more thoughtful, more independent, and to have a greater appreciation for their surroundings. Comparing this research to Walker's study,[10] it was found that similar coping strategies were identified by both the mothers and the siblings. These included arguing, irritability, disrespectfulness, sadness, emotional lability, acting out, aggression, talking and being with others, and playing with friends.

Limitations

Because of limitations of the research study, the data reported were not generalizable to the larger population. This was not a well-represented sample of the American population because it included only the white race,

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low or middle class to upper middle class, two-parent families who were from the same geographic location. The delimitations of this study, which included age of both mothers and healthy siblings, treatment time of the ill child, and living conditions, made for a smaller sample size, which in turn, further limited generalizability.

Conclusions

In summary, research has shown that having a sibling diagnosed with cancer is associated with a change in a variety of behaviors in the well siblings which are considered to be coping strategies. Research in the past has focused on the coping strategies of the parents and the child with cancer. It has been only recently that research has considered well siblings while the child with cancer is still alive and in active treatment. The instruments of this study were designed to document the presence of and change in coping strategies of the healthy siblings. Findings indicated that both mothers and healthy siblings were able to identify a variety of behavior changes. The findings of this study differ from those of previously published studies in that all the mothers in this study were able to identify behavior changes in the healthy siblings.

Implications

The instruments used in this study may be useful clinical assessment tools for nurses who want to identify and assess the behaviors exhibited by the siblings from both maternal and sibling descriptions. The nurses may then use the outcomes to assist the family in coping with the stress of having a child diagnosed with cancer. Nurses need to conduct thorough client-specific assessments of sibling behavior changes exhibited when a child family member has been diagnosed with cancer. This alerts the nurse to the emotional needs of the entire family, not just the ill child. Nurses may then develop interventions that facilitate conversations between family members, which will allow for the identification of changes in behavior.

Identifying the behavior changes of siblings and determining how they compare and differ with maternal descriptions will allow the nurse to educate fellow nurses and families of patients. Educating fellow nurses to identify behavior changes in healthy siblings of pediatric oncology patients promotes thorough assessment of a family, the development and application of nursing interventions, and the evaluation of expected outcomes. Educating the families to identify changes in behavior will help the healthy siblings identify his/her own response to the illness in the family. For nurses to provide effective intervention for the entire family, both the mothers and the siblings need to participate in the plan of care.

There are multiple possibilities for further research. A larger representative sample is needed to increase the generalizability of the study. A more detailed study that includes paternal descriptions and sibling interviews might allow for the identification of additional behavior changes, provide more in-depth data, and further assist the nurse in determining nursing interventions.

Research of behavior changes in well siblings should also include studies involving the effectiveness of nursing interventions. These studies would allow for the assessment of behavior changes of the entire family and allow for nursing interventions that are appropriate for siblings and other family members. Further research using experimental designs would help to delineate the relationships among behavior changes, coping strategies, and family relationships. Behavior changes should also be identified for all children as they progress through each developmental stage along with positive support from their parents and health professionals.

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References

1. Binger CM, Albin AR, Feuerstein RC, et al: Childhood leukemia: Emotional impact on patient and family. N Engl J Med 280:414-418, 1969

2. Cairns NU, Clark GM, Smith SD, et al: Adaptation of siblings to childhood malignancy. J Pediatrics 95:484-487, 1979

3. Iles P: Children with cancer: Healthy siblings' perception during the illness experience. Cancer Nurs 2:371-377, 1979

4. Koch-Hattem A: Siblings' experience of pediatric cancer: Interviews with children. Health Soc Work 11: 107-117, 1986

5. Kramer R: Living with childhood cancer: Impact on the healthy siblings. Oncol Nurs Forum 11:44-51, 1984

6. Walker CL: Siblings of children with cancer. Oncol Nurs Forum 17:355-360, 1990

7. Walker CL: Stress and coping in the siblings of children with cancer. Unpublished Doctoral dissertation, University of Utah, Salt Lake City, 1986

8. Lazarus RS, Folkman S: Stress, Appraisal, and Coping. New York, NY, Springer, 1984

9. Share L: Family communication in the crisis of a child's fatal illness: A literature review and analysis. Omega 3:187-201, 1972

10. Walker CL: Stress and coping in siblings of childhood cancer patients. Nurs Res 37:208-212, 1988

11. Petersen L: Coping of children undergoing stressful medical procedures: Some conceptual, methodological, and therapeutic issues. J Cons Clin Psych 57:380-385, 1991

12. Ryan-Wenger NM: Developmental and psychometric properties of the schoolagers' coping strategies inventory. Nurs Res 39:344-349, 1990

13. Sorensen ES: Children's coping responses. J Pediatric Nurs 5:259-267, 1990

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