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A Structured Group Intervention for Siblings of Children with Cancer

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The current study describes the development and evaluation of a structured group intervention for school-aged and adolescent siblings of childhood cancer patients. Twenty-three siblings participated in a six-week program in which parallel groups of younger (ages 7-11) and older (ages 12-17) siblings were conducted. Defined topics were selected from the clinical and research literature and on the basis of a pre-intervention survey, and were addressed at each session. Methods included facilitated group discussion, art therapy techniques, role playing, and informal social interaction. Pre- and post-measures of cancer-related knowledge, feelings and attitudes towards cancer, and overall mood state were administered. Results indicated statistically and clinically significant improvements in interpersonal problems, intrapsychic preoccupation, disease-related communication, mood, and cancer-related knowledge. Consent and attendance rates, as well as post-intervention satisfaction ratings highlight the subjective need felt by siblings and parents for direct, focused work with this population. Salient issues for siblings of pediatric cancer patients, specific techniques, group dynamics and processes, and staff and parent responses to the intervention program are discussed. The need for replicable, empirically validated interventions for family members of seriously-ill children is emphasized.

KEY WORDS: child group therapy; adolescent group therapy; siblings of cancer patients.

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INTRODUCTION

Theoretical reviews, anecdotal accounts, and empirical studies suggest that chronic childhood illness has a broad impact on the family system and on individual family members (Chesler & Barbarin, 1987; Dolgin & Phipps, 1995; Kazak & Nachman, 1991; Patterson & McCubbin, 1983; Sabbeth, 1984). One model for such investigations had focused on well siblings of children with cancer. This model has proven useful for studying siblings' subjective life experience in the context of illness in the family and for assessing potential risk for the development of psychological disturbance. The underlying assumption is that a child's illness is a source of stress for siblings because of altered family routines, organization, and roles of family members, as well as the disruption of parent-sibling and patient-sibling relationships and interactional patterns (Sourkes, 1980).

With regard to siblings' risk for clinical disturbance, studies have led to divergent and inconclusive results, ranging from findings of significant impairment, to little or no effect, to suggestions that the experience of chronic childhood illness may actually promote some aspects of psychological growth in the well siblings (Cadman, Boyle, & Offord, 1988; Lavigne & Ryan, 1979; Menke, 1987; Sahler & Carpenter, 1987). These divergent findings can be attributed, in part, to conceptual and methodologic differences between studies—most often the use of bivariate research models with varying criteria for psychological disturbance, sample selection and size, and study design (Cadman, Boyle & Offord, 1988; Drotar & Crawford, 1985). In one recent multivariate, controlled study of sibling adaptation (Sahler, Rohgmann, Carpenter et al., 1994), a sample of 254 siblings scored significantly higher on the Child Behavior Checklist (CBCL) Behavior Problems and Social Competence scales than the non-clinical standardization sample, and significantly lower than the CBCL clinical standardization sample on these same scales. The same pattern was found to be true when siblings were compared to comparison samples of youths matched on key demographic variables. Furthermore, siblings were two to four times more likely than non-clinical normative samples to reach criteria for clinical disturbance, depending on their sex and age.

Problem areas experienced by siblings of children with life-threatening illness span a broad range of emotions (Gregg & White, 1987; Kramer, 1984; Sourkes, 1987; Walker, 1988). Some of these lie in the personal experience of the sibling him or herself, while others touch aspects of the sibling's ongoing relationships with significant others in his or her family, social, and school environments. Sibling reactions may include feelings of neglect, alienation, and difficulty communicating needs and concerns, despite what is often a profound "need to know." Siblings may be jealous over the attention and shift of family focus to the child-patient, and may experience shame at the child-patient's appearance or over stigma associated with cancer. At the same time, guilt resulting from feelings of anger and jealousy, fears of heredity and contagion, and sadness over the child-patient's illness, are common. Assuming increased responsibility in daily routines while experiencing frequent separations from parents may result in hurried emotional development, often described in retrospect as having to "grow up too soon." Rescue fantasies and overcompensation speak to the sibling's sense of helplessness and his or her desire for a meaningful role. As pointed out by Sourkes (1980), emotional reactions within the family are often bi-directional, such that feelings of anger, jealousy, and mutual protection from sadness and fear may be shared by family members.

Despite research over the past two decades on the impact of childhood cancer on the family, remarkably few empirical outcome studies have been reported concerning direct intervention with family members, and with siblings in particular. Several programs have been developed for siblings of pediatric cancer patients, most being psychoeducational in nature with some emphasis on support (e.g., Adams-Greenly, Shiminski-Maher, McGowan et al., 1986; Kinrade, 1985). Non-empirical, anecdotal data suggest that these programs can be "helpful" and "informative," and that they achieve high satisfaction ratings from both siblings and parents. However, objective outcome measures to substantiate these claims, as well as pre-post assessments, have generally been lacking. Heiney, Goon-Johnson, Ettinger and Ettinger (1990) detailed a seven-session group therapy program for siblings which received high participant satisfaction ratings but which failed to produce the desired effects on siblings' social adjustment. An exception to these have been the specialized residential camping programs for siblings described by Sahler and Carpenter (1989) and Carpenter, Sahler and Davis (1990). These programs have been demonstrated to positively influence siblings' cancer-related perceptions, fears, and medical knowledge, as well as their overall mood states in comparison to pre-camp levels. Descriptions of proven, replicable intervention programs that can be practically implemented in the treatment setting or the community have been less available in the literature. The objective of this study was to develop a needs assessment-based, structured, time-limited, group intervention for siblings of pediatric cancer patients and to empirically evaluate its effectiveness in terms of siblings' cancer-related knowledge, feelings and attitudes towards childhood cancer, and overall mood state.

METHOD

Subjects

Twenty-three siblings participated in the group intervention following an invitation by psychosocial staff of the pediatric oncology department of a large children's hospital. These subjects were selected from among a larger pool of siblings who had taken part in a descriptive study of sibling adjustment to childhood cancer (Dolgin, Blumensohn, Sahler et al., 1993; Sahler, Roghmann, Carpenter et al., 1994), and were approached for participation in the current study on a consecutive basis. Excluded were siblings who were logistically unable to attend group meetings, or who otherwise did not meet the inclusion criteria. Three eligible subjects were excluded due to either parent or child refusal. Eligibility criteria included: 1. a brother or sister currently in active treatment or within six months of treatment cessation; 2. sibling-participant was aware of child-patient's diagnosis of cancer; 3. consent of parent and assent of sibling-participant; 4. sibling-participant between six and 18 years of age. Subject recruitment was not limited based on the child-patient's specific diagnosis or prognosis. This was done so as to provide a larger sibling pool from which to recruit subjects, and to focus on generalized, ongoing adjustment issues for siblings facing chronic, life-threatening illness within the family. Characteristics of the study sample and of their siblings with cancer are described in Table 1.

Measures

Three measures were administered to group participants and one to participants' parents prior to and following the group intervention. The first administration took place during an individual screening and introductory session with one of the group facilitators within the two weeks preceding the first group meeting. Follow-up assessment using the same measures took place six to eight weeks after the final group meeting. Assessment instruments were adopted from earlier studies with siblings of pediatric cancer patients, and included:

1. Feelings and Attitudes Questionnaire (Sahler & Carpenter, 1989)— This measure consists of 29 closed-ended items which the subject rates in terms of how accurately each statement describes his or her experience since their brother or sister was diagnosed with cancer. The Feelings and Attitudes measure yields four factor scores assessing the domains of interpersonal problems, intrapsychic preoccupation, disease-related communication, and disease-related fears experienced by siblings.

Table 1. Characteristics of the Study Sample (N = 23)

	Child (N = 12)	Adolescent (N = 11)	Total
Sibling Sex			
Male	7 (58%)	5 (45%)	12 (52%)
Female	5 (42%)	6 (55%)	11 (48%)
Sibling Age (yrs.)			
Range	7-11	12-17	7-17
Mean (SD)	8.80 (1.61)	13.62 (1.45)	11.71 (3.02)
Child-Patient Sex			
Male			9 (39%)
Female			14 (61%)
Child-Patient Age (yrs.)			
Range			4-17
Mean (SD)			10.04 (4.85)
Child-Patient Diagnosis			
Leukemia			9 (39%)
Hodgkins Lymphoma			3 (13%)
Ewing's Sarcoma			3 (13%)
Rhabdomyosarcoma			2 (9%)
Neuroblastoma			2 (9%)
Brain Tumor			2 (9%)
Non-Hodgkin's Lymphoma			2 (9%)
Time Since Diagnosis (mos.)			
Range			4-38
Mean (SD)			17.04 (11.86)
Child-Patient Medical Status			
Off Therapy			5 (22%)
On Therapy/Stable			14 (61%)
On Therapy/Unstable			4 (17%)

2. *Cancer-Related Knowledge (Carpenter, Sahler, & Davis, 1990)*—This measure consists of 27 items assessing basic understanding and knowledge concerning pediatric cancer, its causes, common medical procedures, treatment modalities, and treatment side-effects. Approximately half of the items are closed-ended, with the remaining half answered in brief narrative form. Open-ended questions are scored using a scoring manual providing operationally defined response categories and their level of accuracy. A single cancer-related knowledge score is obtained.

3. *Mood Questionnaire (Sahler & Carpenter, 1989)*—This measure consists of 14 items on which subjects describe their mood during the past week by rating a series of positive and negative mood descriptors on a five-point likert scale. Ratings on negatively worded items are subtracted from the sum of positively worded items, such that higher scores reflect more positive mood states. In addition to being administered to the subjects

themselves, this measure was completed by parents of group participants, referring to their child's mood during the past week both prior to, and following, the intervention program.

In addition to these, a Satisfaction Questionnaire (Heiney et al., 1990) was administered to participants during follow-up assessment. This measure tapped subjects' perceptions of the program content and the issues addressed, facilitation, methods, personal impact, and needs for the future.

Group Structure and Procedure

The 23 participants were divided into two age groups, child and adolescent, in order to achieve a degree of homogeneity both in terms of chronological age and developmental impact and issues as they affect younger and older siblings. The children's group (ages 7-11 yrs.) included 12 participants, while the adolescent group (ages 12-17 yrs.) included 11 participants. Groups were facilitated by a clinical social worker, a child life specialist, and a supervising psychologist. Sessions were held in an informal atmosphere in a meeting room away from the hospital ward. In addition to group discussions concerning their experience of the illness and its impact, subjects took part in arts and crafts and other creative activities in order to encourage interaction among participants and to promote nonverbal expression of relevant feelings and themes.

Six group sessions were held on consecutive weeks. The topics addressed in both the child and adolescent group sessions paralleled one another, although the techniques, language, and facilitation methods were adapted to each age group. Specific content areas were chosen based on a review of the literature concerning siblings of children with cancer, as well as on responses of parents and siblings to structured interviews and questionnaires assessing siblings' feelings and attitudes conducted within the framework of a broader study of sibling adaptation (Dolgin et al., 1993). Topics and issues addressed in each of the six sessions were as follows:

Session One: Mutual introductions of group participants, their family members and composition, and their patient-siblings; therapeutic contract; expectations of group members; purpose and plan of upcoming meetings.

Session Two: Feelings and experiences surrounding initial diagnosis and the period immediately following; issues surrounding illness-related communication with others.

Session Three: Focus on the child-patient and his/her illness; changes in the child-patient; nature and causes of the illness; treatment-induced changes and side-effects.

Session Four: Information regarding cancer and treatment; discussion with staff physician and nurse; tour of treatment facilities.

Session Five: Illness impact within the family; changes in role, organization, routines, and mutual relationships.

Session Six: The future—hopes, wishes, fears regarding self and family.

RESULTS

Group Process and Content

Session One: The aim of the first session was to establish rapport among the participants and to introduce their families in general and their ill siblings in particular. The group leaders first identified the participants' common denominator, i.e., their brother or sister's cancer, and the likelihood of its impact on their families. To facilitate the introduction of group members, a familiar, non-threatening task was chosen. Participants were asked to imagine a joint family activity and then to draw it. Group participants then introduced their family members, occupations, and hobbies, and described the shared activity depicted in their productions. The children were especially encouraged to talk about their ill siblings in the context of the family drawing, as well as the nature and course of their illness, and the treatments they had been receiving. Participants responded with their experiences, perceptions, and feelings with regard to the illness and its impact on the family. Seven-year-old Oded, whose brother was suffering from severe physical limitations resulting from a brain tumor, omitted his ill brother from the family drawing. Asked to comment on this, he explained how his brother's handicap prevented him from joining the family in activities in which he took part in the past. Ten-year-old Ophra related to her family's altered routines since her brother's diagnosis, including the fact that they rarely had family meals together at home. Her drawing illustrated the only joint family activity her ill brother could take part in—driving together in the car and eating out on the way to or from the hospital (Figure 1). Eight-year old Edna drew her family watching television, with her ill sister appearing as a tiny, hairless figure near the bottom right margin of the picture (Figure 2). Her sister's bald appearance triggered a discussion of the physical changes caused by the illness and treatment, as well as the reactions these drew from other children and adults in their surroundings. Session 1 was concluded with a discussion of participants' expectations of the meetings and by the definition of the therapeutic contract (e.g., attendance, scheduling, confidentiality). A near unanimous request of the adolescent participants was for additional disease-related information.

Session Two: In this session, participants recounted the circumstances of their discovery of their siblings' cancer (when, who told, etc.), their experiences and feelings surrounding the information they did (or did not) receive at the time, and the atmosphere of communication (open, restricted) with others concerning the issue. Several children found out about the illness indirectly, such as by overhearing adult family members' telephone conversations. Two children were told of their sibling's illness by medical staff. Although some families were characterized by a high level of open communication, it was evident that, for many of the participants, opportunities to discuss the illness with family members were lacking. In fact, several group members admitted their reluctance to discuss the issue with their parents and their wish to shield their parents from additional sorrow and preoccupation. To assist the group members identify the feelings they experienced surrounding the initial period following diagnosis, the Mandala technique described by Sourkes (1991) was utilized. Following a brief guided imagery exercise, each participant divided an empty circle drawn on white sheet of paper into parts reflecting the nature and relative proportions of their emotions during that period. The members then proceeded to color each segment with colors that they felt best represented these emotions, and then to present their designs, as well as what these meant for them, before the group. Two sample Mandalas are presented in Figure 3. The most prevalent categories of affect were fear ("I was afraid he would die"), confusion ("I felt I was in a whirlwind, I didn't know what to think or what to do"), anger ("I felt mad when I saw the world carry on as if business was as usual while my brother was so sick"), and loneliness ("my parents did not seem very interested in what I was doing"). The teenagers also commonly expressed a feeling of hope and future orientation ("I wanted to believe that the treatments would work and that he would get better").

Session Three: This meeting focused on the nature of the illness and beliefs regarding its causes, treatment side-effects, and the physical and behavioral changes participants had detected in their ill siblings. A repeated theme was the ill siblings' demanding behavior ("He thinks he deserves everything") and the participants' outrage at this conduct ("I just can't stand her sometimes"). Anger was often accompanied by an intellectual understanding of the patient's circumstance, leading to a degree of guilt ("I feel bad for feeling this way"). Siblings' identification was expressed in statements indicating that they would not have swapped places despite the intensive attention the illness brought about, or alternatively, survivor guilt ("Sometimes I wish it was me instead of her"). Group members detailed the severe side-effects of chemotherapy, including hair loss, weight changes, irritability, and withdrawal. An emphasis was placed on distinguishing between external, circumstantial, and essential changes in character that had occurred in the ill siblings. Many participants emphasized those attributes that withstood the illness ("she never lost her sense of humor," "he's still the same rascal he always was"). Perceptions with regard to illness causation reflected participants' cognitive developmental levels, ranging from the concrete ("He fell and got a bang") to the more complex and conceptual. Many siblings had their own "private stories" concerning illness causation. One eight-year old girl was convinced the bruise marks with which her sister had returned from kindergarten, as well as the diagnosis of leukemia which these bruises later foretold, were caused by beatings her sister had sustained from other children. A 16-year-old boy admitted being convinced that, after years of parental criticism of his brother's eating habits, he finally developed cancer because of a vitamin deficiency.

Session Four: During this session, participants were led on a tour of the oncology ward and clinic by a staff nurse and physician with the purpose of imparting information concerning the nature of the illness, modalities and rationale of treatment, reasons for side-effects, and common medical procedures (e.g., bone marrow aspirations, lumbar punctures, IV's). Group members presented the tour leaders with questions ranging from heredity

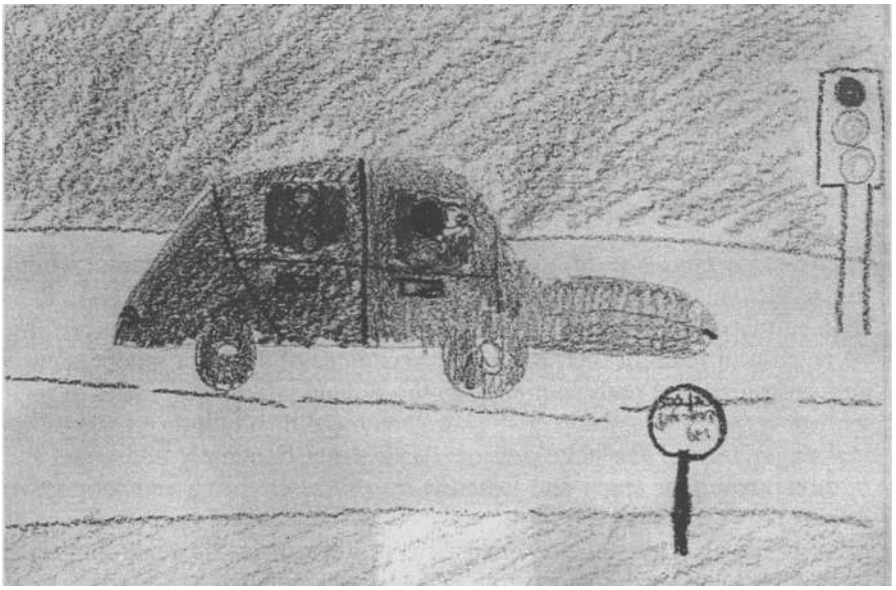

Fig. 1.

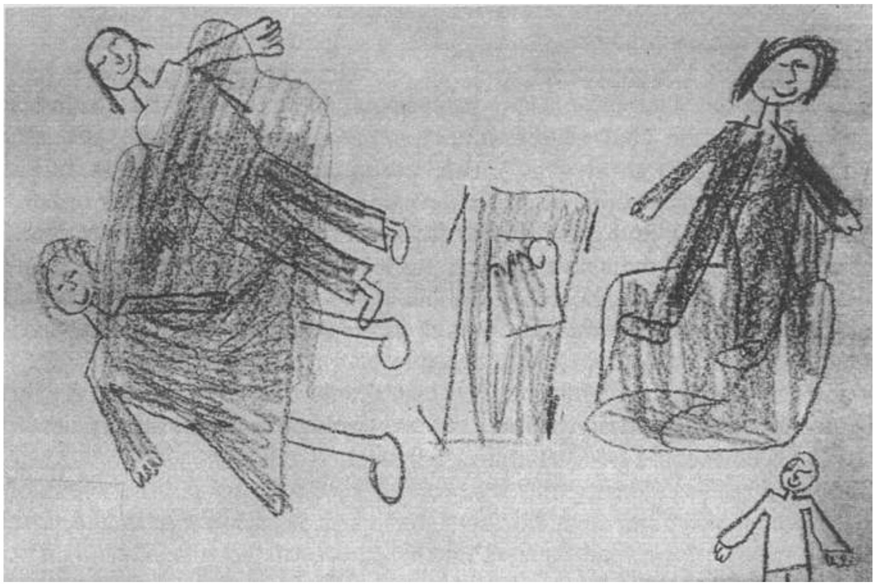

Fig. 2.

to risk factors and prevention in cancer. The doctor spoke in a simple fashion about cell structure and pathology utilizing slides and microscope demonstrations. Group participants, many of whom for which this was their first such experience, were shown the outpatient clinic, examination rooms, blood lab, playroom, parents' lounge, and in-patient unit. The nurse demonstrated various medical procedures utilizing dolls and role playing, and allowing siblings to handle the many different treatment devices and accessories.

Session Five: The fifth group session focused on the dynamics within the participants' families since the diagnosis. In terms of their own role, siblings raised themes concerning increased responsibility and the positive vs. negative aspects of their parents' expectations of them for independence and self-reliance in daily routines. On the sibling-patient axis, issues of protectiveness vs. jealousy emerged, as well as the difficulty in expressing normal anger toward the child-patient. Participants frequently addressed the bi-directionality of anger and jealousy, as well as of caring and supportive efforts between themselves and their ill brothers and sisters. Feelings of relief ("I'm glad it's not me") and guilt ("Why not me?") regarding their own health status in comparison with their ill siblings were shared. Role playing of common family situations affecting them since the illness onset

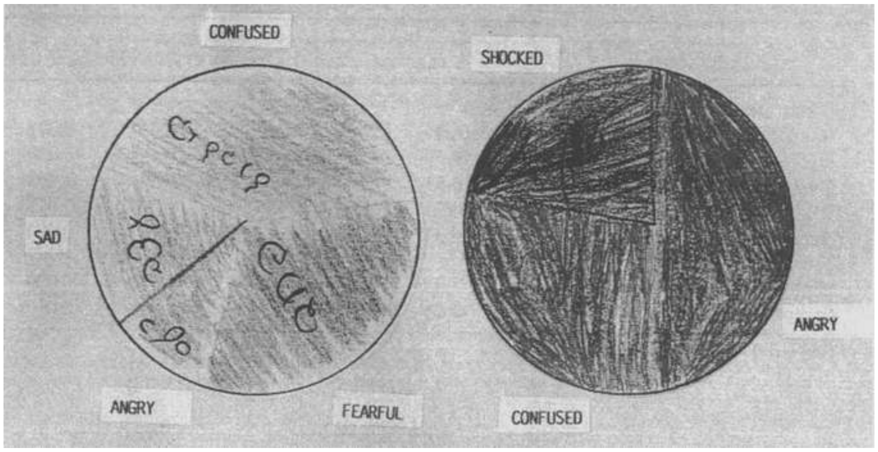

Fig. 3.

demonstrated a desire for attention and nurturance from their parents, as well as the seeming incompatibility of helping parents, shielding them, and drawing from them much needed support and comforting.

Session Six: During the final session, suggestions for facilitating communications between participants and significant others, as well as needs and wishes for the future, were discussed. With regard to the former, letter writing techniques were utilized surrounding the theme of "What I wish I could tell (my parents/my brother or sister/the doctors) but haven't felt I've been able to." A "Things That Can Help" list was generated in which participants raised suggestions for other children and families going through experiences such as theirs. In doing so, potential problem areas and solutions were drawn from themes addressed during previous sessions and incorporated into a book containing stories, pictures, and ideas for brothers and sisters of children with cancer. During this session, the various arts and crafts projects the participants had been working on throughout the group meetings were completed and arranged as an exhibition for the outpatient clinic to signify the siblings' interest and involvement in their common experience.

Empirical Findings

Table 2 describes outcome data on pre- and post-intervention measures of siblings' illness-related feelings and attitudes, cancer-related knowl-

Table 2. Pre- and Post-Intervention Outcome Data for Group Participants (N = 23)

Outcome Measure	Pre M(SD)		Post M(SD)		p < (*)
Feelings and Attitudes					
Interpersonal Problems	16.04	(5.76)	11.39	(4.95)	0.001
Intrapsychic Preoccupation	9.77	(3.51)	5.63	(2.45)	0.000
Disease-Related Communication	6.52	(2.34)	8.26	(3.59)	0.001
Fear	0.96	(1.27)	0.96	(1.27)	NS
Cancer-Related Knowledge	16.00	(8.79)	25.83	(5.98)	0.000
Mood State					
Sibling-Report	3.22	(11.00)	14.78	(6.75)	0.000
Parent-Report	-3.43	(10.39)	18.19	(6.92)	0.000

(*)Paired T-Test Probability

edge, and self- and parent-report of sibling mood states. All measures, with the exception of the fears subscale of the Feelings and Attitudes Questionnaire, indicated significantly positive intervention effects. It is noteworthy that the fears subscale, which showed no pre- to post-test treatment effects, received extremely low ratings at both points, suggesting that siblings may be less preoccupied with fears such as heredity or contagion than generally thought to be the case. Table 3 presents data on the post-intervention Satisfaction Questionnaire which indicated participants' generally high satisfaction levels.

DISCUSSION

The needs of family members of chronically-ill children in general, and of pediatric cancer patients in particular, have been widely discussed in the literature. For the most part, these needs and experiences have been described in terms of overall psychosocial adjustment, with some emphasis on family dynamic and risks factors (e.g., Chesler & Barbarin, 1987; Dolgin & Phipps, 1995; Sahler, Roghmann, Carpenter et al., 1994). While intervention studies with family members have been generally scarce, several reports of programs with siblings have offered useful guidelines in terms of the objectives, content, and strategies relevant to work with this population (Adams-Greenly et al., 1986; Heiney et al., 1990; Kinrade, 1985). The current study incorporated themes from these earlier descriptive and treatment studies with siblings, as well as other techniques applicable to children in crisis (e.g., Sourkes, 1991), taking this further step by empirically evaluating a relatively brief, structured program within a pre/post treatment

Table 3. Post-Intervention Satisfaction Evaluation by Group Participants (N = 23)

Item	Rating (*)
Group would be useful to other sibs of children with cancer	3.74
Would attend another group with these leaders	3.70
Interested in attending another group in the future	3.64
Glad I participated	3.83
Satisfied with the group	3.76
Felt less alone learning others felt similar to me	3.33
Learned other ways to deal with problems	3.43
Felt supported by the group members	3.57
Could share thoughts in group that I couldn't share with most people	3.13
Felt I could cope because I saw that others were coping	3.50

(*)Mean Ratings on 1-4 Scale (1 = Strongly Disagree, 2 = Disagree, 3 = Agree, 4 = Strongly Agree)

research design. Results confirm, with statistical as well as clinical significance, gains in cancer-related knowledge, mood, communication, and intra/inter personal feelings, following the group sessions. A major focus of the sessions—that of facilitating expressiveness within the group and of promoting siblings' communication skills in the context of their own families—was reflected in improvements in subjective attitudes towards illness-related communication and in self-reported and parent-reported mood states. These results support earlier findings of the relationship between family environment, expressiveness, support, and sibling adjustment (Dolgin et al., 1993; Horowitz & Kazak, 1990).

The subjective need of siblings for the type of support offered by the current program was reflected both in post-treatment evaluation of participant satisfaction, as well as in the consent and attendance rates, which neared 100%. Of 24 siblings originally enrolled, only one dropped out following the first session. This was a seven-year-old sibling of a very newly diagnosed patient who attended under considerable parental pressure. Intervention with siblings, particularly young ones, at such an early stage in the illness may be premature and overwhelming, leading to resistance. In terms of the dynamic processes during the group sessions, closeness, trust, and intimacy among participants were promoted by the art-therapy components of the intervention. Participants assisted each other, commented on each other's work, and interacted during these creative activities in a friendly and relaxed manner. As the sessions progressed, a shift could be observed from communication via the group facilitators, to direct interpersonal exchange. The bonding that developed among group members was well evident at the dinner party that was organized several weeks after the final group session, and to which patient-siblings were also invited, at the participants' initiative.

The current program was conducted within the context of a large pediatric cancer treatment facility. While the department staff was generally in agreement that this program met a previously unanswered need, there was some initial anxiety that the group might activate or exacerbate distress among some siblings that had been otherwise managed through denial or distraction. For some staff, the fear was expressed that the issues raised in the group might burden the earlier depleted parents who would end up having to "pick up the pieces" after the group had terminated. In fact, informal follow-up contacts with the parents confirmed that most were generally quite relieved by the fact that professional attention had been given to their well-children, whose concerns they feared had been neglected. An expectation of an important minority of parents was that the intervention program would improve their well-children's conduct, which they viewed as inconsiderate and overly demanding. For these parents, guidance was offered to complement the group process that their children were undergoing. Many parents sought information concerning their children's progress, and this was provided within the parameters of confidentiality set out in the therapeutic contract with the participants. The high satisfaction ratings of the participants, as well as the positive reception by parents, served well to alleviate lingering staff anxieties about any potential adverse effects of the program.

While the current study did employ a pre/post assessment design, non-specific intervention effects can not be ruled out. Thus, future studies may be refined by the use of no-treatment, standard treatment, or wait-list control groups. Also, while post-intervention effects were evident at the 6-8 week follow-up assessment, the durability of these changes over time should be evaluated. The structure and techniques employed in the current program provide a model that can replicated in most treatment settings with a minimum of resources or expenditure. In this case, the costs of the program (e.g., transportation, refreshments, dinner party) were underwritten by the department's parents organization. Progress in the development and implementation of intervention programs with family members should keep pace with descriptive, predictive, and risk-factor studies (e.g., Sahler et al. 1994). Focused, empirically validated intervention programs for parents of children with cancer, such as that currently being tested by Sahler and colleagues (in progress) are particularly lacking, yet most important given the parent's pivotal role in patient, sibling, and overall family adaptation.

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