

The Emotional Experience and Perceived Changes in Siblings of Children With Cancer Reported During a Group Intervention

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Purpose/Objectives: To examine the experiences and perceived changes in siblings of children with cancer while participating in a group intervention program.

Research Approach: Repeated observations during group participation and content analysis.

Setting: A tertiary pediatric health center in Ontario, Canada.

Participants: Twenty-two siblings (aged 7–18 years) of children with cancer.

Methodologic Approach: Siblings participated in the Siblings Coping Together program, an eight-week group intervention designed for this population. Data consisted of materials completed by siblings (49 homework sheets, 33 pieces of artwork), and 31 logs recording events within group sessions.

Findings: Three categories emerged from the data: (a) siblings' emotional experience (related to cancer, their affected brother or sister, and the family), (b) siblings' role change (increased responsibility; becoming a caregiver, helper, and entertainer for the ill child), and (c) changes during the eight-week group intervention (bonding with other siblings; increased participation, trust, and interactions; increased coping strategies).

Conclusions: These findings provide rich insight into siblings' own views of changes in themselves and within the family, as well as the perceived benefits of group participation.

Interpretation: Methodologically, this study demonstrated that the inclusion of visual materials as data is a valid methodology for future research. Clinically, these findings can help nurses in their daily care of children with cancer and their families.

A diagnosis of childhood cancer and its treatment is a devastating experience for the ill child, parents, and siblings, and it can lead to psychological difficulties (Alderfer et al., 2010; Prchal & Landolt, 2012). Siblings have reported a reduction of parental attention (Chesler, Allswede, & Barbarin, 1992; Freeman, O'Dell, & Meola, 2000; Sargent et al., 1995; Sloper, 2000); missing parents and the ill child when apart (Havermans & Eiser, 1994; Prchal & Landolt, 2012); a sense of jealousy, anger, and loneliness (Chesler et al., 1992; Dolgin, Somer, Zaidel, & Zaizov, 1997; Havermans & Eiser, 1994; Sloper, 2000); and a loss of a family way of life (Woodgate, 2006). Siblings have also reported feeling worried (Nolbris, Enskär, & Hellström, 2007) and guilty for the illness (Bendor, 1990). These experiences and emotional responses may lead to psychological maladjustment in a subgroup of siblings (Alderfer et al., 2010; Alderfer, Labay, & Kazak, 2003; Kaplan, Kaal, Bradley, & Alderfer, 2013; Sidhu, Passmore, & Baker, 2006). Combined, these studies suggest a need for developing preventive interventions targeting the psychosocial difficulties of siblings of children with cancer. Systematic reviews of the literature have reached similar conclusions (Barlow & Ellard, 2006; Houtzager, Grootenhuis, & Last, 1999; Packman, Weber,

Wallace, & Bugescu, 2010; Sharpe & Rossiter, 2002; Vermaes, van Susante, & van Bakel, 2011). Houtzager et al. (1999) and Prchal and Landolt (2009) have documented psychosocial interventions for these siblings since the mid-1980s. Great diversity exists across these studies from heterogeneous small samples that may include siblings as part of the family (Kazak et al., 2005) to siblings of children with diverse health conditions, including cancer (Williams et al., 2003). In general, these studies had limited scientific rigor. The current authors developed an evidence-based, manualized intervention program exclusively for siblings experiencing pediatric cancer called Siblings Coping Together (SibCT) (Chung, Miranda, Fleming, & Barrera, 2004). The authors also assessed feasibility and intervention outcomes (Barrera, Chung, Greenberg, & Fleming, 2002; Barrera, Chung, & Fleming, 2005; Salavati et al., 2014).

As part of a new study investigating the efficacy of the SibCT intervention, the objectives of this study were to examine siblings' experience of having a brother or sister with cancer and their view of the group intervention's impact on them. In this article, the child with cancer is referred to as the ill child. Using qualitative methodologies, the authors addressed the following research questions:

- What are siblings' feelings and experiences regarding having a brother or sister with cancer?
- Do they perceive changes in their role within the family under those circumstances?
- Do their feelings and responses change during the course of the group intervention?

Methods

The current sample was purposively selected from the sample of the larger group intervention study. The larger intervention study included eight groups; of these eight groups, four were selected for this study based on equivalent group size, siblings' age and gender, diagnosis of the ill child, and sociodemographic variables (e.g., ethnicity) representative of the larger sample. Twenty-two siblings participated from the four intervention groups. Siblings were included in the larger study if they had a brother or sister who had been or was being actively treated for cancer at the Hospital for Sick Children in Toronto, Ontario, Canada, a large oncology center; was at least three months postdiagnosis; and was expected to survive for at least one year from study enrollment. Institutional ethics approval was obtained prior to enrollment. Ages in the current sample ranged from 7–18 years ($\bar{X} = 11.7$, $SD = 2.64$) at the time of recruitment, and 11 participants were male. Nineteen siblings came from intact families, and 12 of the families reported to be Caucasian. Ten participating children were the

only sibling for the ill child, five participating siblings had two other siblings, and seven had three or more siblings. Most participating siblings ($n = 16$) were older than the ill child. Regarding the clinical characteristics of the ill child, leukemia/lymphoma was the main diagnosis, and 11 of the ill children were on active treatment but stable.

Siblings Coping Together Group

SibCT has been previously described in great detail (Barrera et al., 2002; Barrera, Fleming, & Fahn, 2004; Chung et al., 2004). SibCT is a manualized, group cognitive-behavioral program with an emphasis on reconstructing siblings' distorted cognitions (e.g., "I'm not important."), problem solving, and building coping strategies to manage difficulties through fun activities, arts and crafts, and role playing within a safe environment. It consists of eight weekly two-hour group sessions and a reunion three months later. Groups take place in a pediatric hospital setting run by two facilitators (e.g., psychologists, graduate students, research assistants). Each session focuses on a specific theme (e.g., medical information related to cancer, cancer in the family) (manual available upon request).

Data Source

Data for this study consisted of individual and group materials, homework completed by siblings, and group logs completed by group observers and/or facilitators and selected from early (1–3), middle (4–5), and final group sessions (6–8) to ensure that data were representative of all sessions. Materials completed by siblings consisted of visual (e.g., drawings, collages) and text (e.g., description of an activity) materials, or both (e.g., drawing accompanied by a description), which were completed individually (e.g., homework) or as a group (e.g., mind map, posters). For example, during session 4, siblings created a "feelings tree" by writing feelings on paper leaves that were then pasted on a drawing of a tree. Thirty-three group materials were analyzed.

Homework, presented to siblings as "funwork," was assigned at the end of each session and discussed as a group during the following session. For example, the funwork for session 3 was to write or draw about "how cancer met your family." Some siblings wrote a story about when their brother or sister was diagnosed, some drew pictures about their experience with written descriptions, and others just talked about it in the group even if they did not bring anything with them. However, most participants completed the funwork on a weekly basis. At the end of the session, participants were asked if the research team could make a copy of their funwork. Some participants chose not to share

their funwork, so their work was not included in the analysis, but they were still active group participants. Forty-nine funwork sheets (completed by 10 participating siblings) were analyzed.

Logs were completed by observers via a two-way mirror and occasionally by group facilitators. Observers and facilitators were trained to describe what they heard and saw during the session (e.g., group participation, observations of individual participants and the group as a whole). To ensure reliability of the logs, logs were completed by an observer and a facilitator on at least one session per cycle. Although the observers' logs were, in general, longer and more detailed than the facilitators', the identified issues were consistent across informants. Logs were analyzed by a doctoral student and research assistant not involved in writing the logs. Thirty-one logs were analyzed.

Data Analysis

Although children's drawings and visual materials have traditionally been used in the clinical setting as projective tests or indicators of developmental level and psychological adjustment, they have rarely been used as research data (Merriman & Guerin, 2006). Projective drawings have been used as research data to assess the emotional well-being of siblings of children with cancer who attended a camp (Packman et al., 2008). Spontaneous drawings and visual materials can offer "a different kind of glimpse into human sense-making than written or spoken text do" (Kearney & Hyle, 2004, p. 362).

In this qualitative study, the authors used content analysis techniques for text, suggested by Cavanagh's (1997) and Merriman and Guerin's (2006) adaptations of content analysis for visual material. Content analysis aimed to develop themes, subthemes, and patterns that capture a conceptual understanding (Kearney & Hyle, 2004). Analysis of text (e.g., logs completed by group observers and facilitators) and visual material consisted of an iterative process, beginning with two researchers independently reviewing the text and visual materials to obtain an in-depth understanding of the emerging concepts and themes. For example, regarding the visual materials, expressions on drawn faces, the presence of specific objects (e.g., medical equipment), and context of the drawn figure (e.g., a child alone in his room while the family is in another room with a bald child) were considered with regard to a child's picture. Visual materials could suggest feelings of sadness and exclusion within the family.

The logs and visual materials were coded individually and across sessions, following an integrated coding system to identify, contrast, and confirm emerging categories and themes. When coding differences existed, discrepancies were discussed with a third

researcher until final consensus was reached. For further test trustworthiness of the data, peer debriefing was conducted with the members of the larger research group, some of whom had either observed or facilitated groups (Lincoln & Guba, 1985).

Results

Three major categories emerged: (a) siblings' emotional experience, (b) siblings' role change within the family, and (c) changes during the eight-week group intervention. These categories and specific themes and subthemes are described in the current article.

Siblings' Emotional Experience

Personal losses and sense of exclusion from the cancer experience: Siblings expressed personal losses during group discussions, such as not being able to participate in activities they used to do (e.g., gymnastics, soccer) because their brother's or sister's treatment took priority within the family or fearing their brother or sister would feel bad because they could not join in. This was also captured in the logs.

Siblings varied in the degree to which they felt included or excluded from the cancer experience. They talked about wanting to be included and to understand what was happening with the ill child. This was best captured by a 14-year-old girl who said, "[After the diagnosis], my whole world was turned upside down. I wanted to know as much as possible about cancer so that I could at least come to terms with what I was up against." Siblings expressed how they often could not see their family for extended periods of time and how this made them feel left out, dismissed, and brushed aside. A 12-year-old girl said, "Since I could not see [my brother] for a month or two, I got the most affected because everyone knew what was going on except for me." Conversely, participants described a sense of inclusion during group discussions by visiting the ill child at the hospital, helping with medical care, and being a part of family discussions.

Siblings described during their group participation feeling at some point confused, ambivalent, or having "mixed feelings" throughout their experiences with cancer. For example, one sibling stated that he was happy that his brother was out of the hospital but also mad, anxious, and scared. A 9-year-old girl drew four faces depicting her feelings about cancer, which included feeling joyful, upset, sad, and happy.

Losses related to the ill brother or sister: Siblings expressed a variety of feelings specifically regarding the ill child, from missing the ill child ("Since cancer, my sibling and I spend less time together.") to feeling less important, overlooked, ignored, and less loved

(“My hurt is not noticed,” “My family now gives my sister more attention,” “Mom is more nice to my sibling,” and “A bad thing about having a sibling with an illness is being ignored.”). Siblings also perceived themselves as having fewer privileges than the ill child (“They always get what they want,” and “Mom sides with brother.”). Siblings expressed feeling frustrated that people ask repetitive questions about the ill child (e.g., “How is your [brother or sister]?”), that “everyone talks about [my brother’s or sister’s] cancer all the time,” and that people rarely “check in on me.”

Conversely, siblings also described feelings of guilt, as if they had done something wrong (“It’s my fault.”) and feelings of empathy and worry for the ill child, particularly when being left out of normal activities. A 13-year-old boy said, “I feel sad for my sister because, when she gets older, she will get mad because everyone might walk, and she might not be able to.” Many questions were posed, including, “How long will this affect my brother or sister?” “Do kids get better?” and “Does it hurt?”

Finally, siblings talked about hope, as exemplified by an 11-year-old boy, who said, “In the future, I hope my brother can walk, and I do not have to worry about him, and he might not feel bad about himself.” During an activity, a sibling built a boat with a tumor, explaining that, when the boat is in the water, the tumor will float away as he hoped his sister’s cancer would.

Losses related to family unit: During group discussions, siblings expressed a perception of being a burden in the family, not wanting to trouble others with their personal struggles, and trying to “be good” to avoid upsetting their parents. Siblings expressed how this kept them from talking about their issues at home. This is illustrated in a log that noted, “She stated that she did not like to open up to her family because she did not want to burden them with her problems.”

Siblings demonstrated awareness of distress in other family members. This is illustrated by several individual quotes, including “Dad wants to help more but is becoming more stressed out; there is less money for things”; “Mom is more reactive to situations than before; she has more to do around the house”; and “My family went from joyful to sad and frustrated.” Siblings also recognized the impact of family stress on themselves. One participant said, “I must walk on eggshells around my parents because parents can be irritable.”

Siblings’ Role Change Within the Family

Increased responsibility: Siblings frequently described an increase in responsibility, such as helping

more around the house and taking on tasks that the ill child had previously been responsible for. A 12-year-old girl wrote, “Me and my brother were treated the same. Now I have to do more chores.” Some siblings said during group discussions that these additional responsibilities led to a strain on their relationship with the ill child. For some older siblings, the extra responsibilities were welcome. A 17-year-old girl said, “I feel proud to be someone my family can count on.”

Caregiver helper: Siblings talked about taking on and adapting to new caregiving roles and the ways they help care for the ill child. A 12-year-old girl reported helping her brother by “getting his stuff for him when he’s not feeling well, rushing to him when something bad happens, and visiting him as much as possible.” Some participants described the toll their caregiving duties take on them. A 13-year-old boy said he was “overwhelmed by all the extra help he gives his sibling.” Others reported having to make a choice between caring for the ill child and caring for themselves. A log noted that a 10-year-old boy said, “His mom was doing laundry, and his little sister was crying [while he was caring for her], but the school bus was waiting to take him to school.”

Entertainer for ill child: Some siblings reported spending more time with the ill child than before cancer by acting as an entertainer to distract him or her from the disease and treatment. An 11-year-old boy stated, “It is different because I play with her more often instead of doing other stuff like going outside.” A 13-year-old girl said, “At the hospital, I visit him and make him laugh and smile, so he won’t feel bad.”

Changes During the Eight-Week Group Intervention

Bonding with each other: During the course of eight weekly group sessions, siblings were noted to bond with each other over shared experiences. Initially, siblings talked about organized cancer-related experiences they had in common (e.g., camp, sibling days). As sessions progressed, siblings were more willing to share negative emotions and helped each other seek solutions. For example, siblings talked about “hiding” in places alone to cry and be sad (e.g., in a closet, on a rock in the park). Participants demonstrated empathy and understanding for each other. During an activity where siblings created feelings masks, many siblings described showing others happiness when really they felt sad, angry, or confused on the inside. Siblings reported that they “could take the mask off” when they were alone, around close friends, and in the group.

Increased participation and interactions among group members: Initially, at sessions 1 and 2, most siblings were described as “withdrawn” and “quiet.”

While participating in activities, they hesitated to share or talk about themselves. During sessions 2–4, a gradual change was noted. Siblings were becoming more relaxed and willing to express their thoughts and feelings (“interested in each other’s questions” and “opened up more than in previous weeks”). Siblings also began to see themselves as group members. An excerpt from a session 3 log described the facilitator asking the participants whom the group was for. Participants at first replied “me” and then quickly said “us,” illustrating their interconnectedness.

At sessions 5–7, siblings were often described as “eager” to participate, share, and raise issues “in closer proximity to each other” and were “very comfortable with one another” and “sharing more personal experiences.” This is illustrated by a sibling who shared a photo album of his brother’s 30 days of radiation. There were also increased gestures of support to one another. In session 5, a 17-year-old girl talked about how she “most enjoyed the cooperation and open communication amongst group members.” At session 8, siblings expressed sadness about the group ending and exchanged contact information to continue communication after the intervention.

Increased coping strategies to manage their feelings: Evidence from text and visual materials suggests that siblings were learning problem-solving and coping strategies to deal with their cancer experience during the eight-week group intervention. The following quotes illustrate siblings’ new perspectives in session 6: (a) “When people ask weird questions about cancer, you could either tell them you do not want to talk about it or take it as a positive [comment] and educate them”; (b) “When you miss school to go to the hospital, you can call a friend for the homework”; and (c) “When you feel overwhelmed by all you take on, you can listen to music, take a deep breath, think of something positive, play games to distract yourself and balance time.” As captured in the logs, by session 8, siblings were acknowledging their parents’ efforts to show them love by bringing them to the group and spending time with them traveling to and from the group. Siblings also demonstrated more confidence expressing their views and participating in problem solving. This is illustrated by a 9-year-old boy who was able to stand in front of his parents during his group’s graduation and articulate that “siblings sometimes feel lonely because parents are at the hospital, and often siblings feel left out and spend a lot of time alone at home.”

During the last session of the group, siblings were offered the opportunity to give advice to other children in their situation by writing a “letter to future siblings.” Some siblings wrote the following: (a) “Don’t feel that your parents are giving more attention to your sibling even if it looks like it”; (b) “Try not to get frustrated or

hopeless”; (c) “Compromise with your family, and remain calm”; and (d) “Find someone to talk to; it’s better than keeping anger and sadness inside.”

Discussion

This study describes how siblings perceived their experiences of having a brother or sister with cancer and what changes they noted throughout their eight-week participation in the group. Analysis of text and visual materials made by siblings and session logs completed by observers and facilitators provide rich and valid data for examining siblings’ perceptions and group process. Using participant-produced spontaneous visual material as data is rare (Kearney & Hyle, 2004). In this study, content analysis of text and drawings was feasible, and the rich data contributed to further understanding of siblings’ views and experiences with cancer and how their views and behavior changed during the eight-week intervention.

Although a number of previous studies have described emotional reactions experienced by siblings of children with cancer (Nolbris et al., 2007; Prchal & Landolt 2012; Sloper, 2000), this study further documents how, as siblings became more comfortable within a group intervention, they gained greater insight about their personal losses and feelings of confusion, frustration, and being left out, as well as their personal gains and insights. Siblings also reported feelings of guilt and worry about the ill child and increased responsibilities at home, confirming previous reports of gaining maturity and empathy (Bendor, 1990; Labay & Walco, 2004; Nolbris et al., 2007). Of note and not previously reported, siblings also described assuming new roles within the family (caregiver helper and entertainer for the ill child), acknowledged sacrificing their own time and needs to spend time with the ill child, and described how their perceptions of distress in their parents affects them. These in-depth reflections further attest to increased maturation in these siblings related to the cancer experience beyond what was previously reported.

Finally, specific to the context of the data, siblings acknowledged benefits for themselves related to participating in the group intervention (e.g., increased problem solving and coping), along with the additional bonus of positive attention from parents while traveling to and from the group. These insights regarding perceived benefits of group participation, as well as their reflections regarding the cancer experience, may serve to foster resilience in these siblings and prevent risk for developing severe psychological difficulties in the future.

The richness and triangulation of the data (multiple informants, text, and visual materials) during several

observational points afforded the authors an opportunity to see changes in the participants' views of the cancer experience as they became more comfortable in the group setting and acquired new strategies to deal with their circumstances. In addition, this study illustrated how the group became not only a trusted environment, but also a source of support, which has previously been found to serve as a resilience factor (Alderfer & Hodges, 2010; Barrera et al., 2004).

Limitations

The findings of this study need to be considered in light of some limitations. The authors acknowledge the potential for confounding siblings' perceptions of their experience with cancer with the impact of group intervention participation. Future studies could explore siblings' experiences using repeated group interviews without the intervention focus. This would allow siblings time to become comfortable in the group setting as they reflect on the cancer experience. Explicit awareness of the potential bias of the investigator as an interpreter of the data should also be maintained. In this study, having several informants and sources of data, along with continued discussion and peer debriefing, protected the validity and trustworthiness of the data throughout analysis.

Implications for Nursing

Methodologically, these findings illustrate how content analysis can be conducted with visual material to triangulate data from various sources. Participant-produced drawings and visual materials offer rich insight into the participants' perspectives, particularly for young children or those who may find expressing themselves easier with visual material. Combined with the positive quantitative results of the randomized, controlled trial, these findings could guide improvement of psychosocial services for siblings. This information may assist pediatric oncology nurses in dealing with siblings in their practice within the family-centered care model. Understanding siblings' own views of the impact of cancer on them can help healthcare professionals, particularly nurses, effectively address siblings' issues and facilitate family adjustment. For example, findings show that siblings want to feel included in the cancer experience. Therefore, nurses could acknowledge siblings as important members of the family and encourage parents to include siblings in scheduled appointments and medical care of the child with cancer. Finally, the current findings may provide knowledge for nurses to draw on when addressing parents' questions about siblings and educate parents about siblings' needs throughout the cancer trajectory.

Knowledge Translation

- A better understanding of siblings' perspectives regarding their experiences with cancer can encourage nurses to involve siblings in psychosocial care, and the beneficial effect of group intervention for siblings may guide the improvement of psychosocial services for them.
- Understanding siblings' own views of the impact of cancer on them and the beneficial impact of the intervention may help pediatric oncology nurses facilitate sibling and family adjustment.
- Mixed method methodology, including text and visual qualitative data, along with quantitative evidence of effectiveness of group intervention programs for siblings (reported elsewhere), is essential for the evaluation of psychosocial interventions.

Conclusion

This study examined siblings' experience of living in a household where a brother or sister is or has been treated for cancer, how they are coping or have coped with the experience before the group, and how they benefited from group intervention and changed over time as they became more comfortable and acquired new coping strategies. These findings contribute to a better understanding of the personal experience of siblings when a brother or sister is diagnosed with cancer, as well as the process of group intervention as siblings acquire new knowledge and strategies.

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