

The Experience of Therapeutic Support Groups by Siblings of Children with Cancer

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The bond between siblings is unique and full of different emotions (Ainsworth, 1991; Bank & Kahn, 1997; Bowlby, 1969; Cicirelli, 1995; Giovanola, 2005; Lindsay & MacCarthy, 1974; Nolbris, Enskär, & Hellström, 2007; Sanders, 2004). When a child in a family contracts cancer, all the attention turns to the sick child (Giovanola, 2005; Nolbris & Hellström, 2005; Spinetta, 1981), and the parents' time with the other children decreases (Giovanola, 2005; Iles, 1979). In this situation, the sibling's role changes constantly, during as well as after the different phases of cancer therapy (Nolbris & Hellström, 2005).

To help them understand their situation, siblings of the sick child need someone with whom they can confide (Murray, 1998). A sibling group offers a method for siblings to have this opportunity in a supportive environment.

Background

Participation in a sibling group has been shown to decrease anxiety, depression (Barrera, 2000; Barrera, Chung, Greenberg, & Fleming, 2002; Houtzager, Grootenhuys, & Last, 2001), behavioral suppression, and fear of cancer (Barrera, 2000; Barrera et al., 2002). Going to a camp with other children who had a sick sibling was also a positive experience, as was

When a child is diagnosed with cancer, the whole family, including siblings, lives in fear of how the cancer will affect the sick child and how it will influence other family members. The aim of this article is to describe the experiences expressed by the siblings in a support group environment when their families have or have had a child diagnosed with cancer. Fifteen siblings 8 to 19 years of age with a brother or sister who was receiving treatment for or had died from cancer were interviewed after participating in therapeutic support groups. These interviews were conducted two weeks after the last group interaction and were analyzed using qualitative content analysis. Regardless of gender and age, the siblings felt a sense of belonging and comfort by being in a group, which they appreciated. They were able to share their experiences and help each other with advice and encouragement. They all drew strength from each other. A therapeutic support group for siblings of children with cancer is beneficial. Follow-up interviews with the siblings indicated they found the groups helpful in coping with their situation.

interaction with a group of people of different ages in a similar situation (Adams & Deveau, 1987; Freeman, O'Dell, & Meola, 2003; Havermans & Eiser, 1994; Mahon & Page, 1995; McKeever, 1983; Murray, 1998, 2001, 2002; Nabors et al., 2004; Nolbris & Hellström 2005; Sidhu, Passmore, & Baker, 2006; Sloper 2000).

Social support is very important for the siblings and helps them talk about and deal with their situation (Barrera et al., 2002; Murray, 2001). Creed, Rufflin, and Ward (2001) showed a sibling camp was helpful in dealing with the grief during and after the sick child's treatment, even in cases when the sick child eventually died. The siblings felt they were able to express their emotions by showing their sadness, anger, or happiness in a way they could not do before. It is beneficial for

siblings to discuss their recurring and painful thoughts on jealousy and unfairness (Kübler-Ross, 1997). When they meet others in the same situation, the siblings realize they are not alone in their loss. Other benefits of groups could be the opportunity to ask questions in a safe environment in which participants do not have to worry about annoying or hurting anyone. In a study of focus groups for parents, Sidhu et al. (2006) found parents also realized a camp gave siblings time and space for self-reconciliation.

Experiences from sibling support groups need to be investigated further from the siblings' point of view. The aim of the study was to describe the siblings' experiences of their involvement in a therapeutic support group when the family has or has had a child with cancer.

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Table 1.
Presentation of the Participants and the Sick/Deceased Children or Adolescents

Participant (Group Number)	Sibling's Gender and Age at Interview (Years)	Age of Sick Brother or Sister (Years)	Time from Diagnosis to Interview (Years)	Diagnosis	Time since Death (Years)
1 (1)	M 13	18	4.2	Colon cancer	1.2
2 (1)	M 18	13	3.4	Lymphoma	2.0
3 (1)	F 18	22	5.2	ALL, BMT	2.1
4 (1)	F 19	19	11.7	ALL	2.11
5 (1)	M 14	21	4.2	ALL	3.4
6 (1)	F 11	21	4.2	ALL	3.4
7 (2)	F 13	10	1.2	Ewings-sarcoma	
8 (2)	M 12	14	1.6	PNET, medulloblastoma	
9 (2)	F 19	15	0.5	Lymphoma	
10 (3)	F 10	3	0.9	Neuroblastoma	
11 (3)	M 8	3	0.9	Neuroblastoma	
12 (4)	F 15	9	0.8	ALL, BMT	
13 (4)	F 12	9	0.8	ALL, BMT	
14 (4)	F 11	4	0.7	AML	
15 (4)	F 9	4	0.7	AML	

Note: ALL = acute lymphoblastic leukemia; BMT = bone marrow transplantation; AML = acute myeloid leukemia; PNET = primitive neuroectodermal tumors.

Method

New knowledge can be extracted from insights into the siblings' experiences of participating in a therapeutic support group using a descriptive qualitative approach with individual interviews (Taylor & Bogdan, 1984, 1998). The arrangement of the therapeutic support group meetings for the siblings in this study was in agreement with the focus group technique. A moderator guides the conversation group. The moderator must have experience in the subject matter, including knowledge about normal child and adolescence development, and be flexible, listen actively, and provide neutral answers to group questions (Morgan, 1993).

The focus group method has been practiced and proven to work well in the treatment of individuals with emotional needs (for example, children in rehabilitation clinics for substance abuse) (Agar & MacDonald, 1995) and professional guidance for nurses in intensive care units (Lantz & Severinsson, 2001). In a study by Woodgate (2006), focus groups were used as a method to give siblings an opportunity to talk about their feelings and help them through their brother's or sister's childhood cancer.

Setting and Participants

Siblings 8 to 19 years of age of a child who had been diagnosed with cancer at the Department of Pediatric Oncology, Queen Silvia Children's Hospital in Sweden, were invited to take part in the study. Siblings of children who had died from cancer were also invited to take part. Follow-up interviews after the series of group meetings aimed to extract information directly from the participating siblings about their experiences (Docherty & Sandelowski, 1999; Mishler, 1986; Nolbris et al. 2007; Patton 2002; Scott-Findlay & Chalmers, 2001). The individuals were selected for the study based on different diagnoses of cancer, treatment phases, and whether the sick child had died. Participants had to be able to come to the hospital and speak Swedish. Each group needed to include both boys and girls. The time from diagnosis needed to be two to seven months. For siblings who had lost a brother or sister, six months must have elapsed.

Two nurses from the pediatric oncology unit asked 25 families about participating in the study. Of these, 14 families declined participation (13 siblings, 3 parents). Some siblings

were unable to participate due to the distance to the hospital, and others were afraid of what would happen in the group or to them. Some parents did not think it would be good for their child. The siblings and legal guardians were informed about the study verbally and in writing. They were informed that participation was voluntary and could be stopped at any time, and that confidentiality was assured. In total, 15 siblings from 11 families, with 5 boys and 10 girls 8 to 19 years of age gave their informed consent to participate.

The individuals in the study were assigned to one of four therapy groups. Each group had one pair of siblings from the same family (see Table 1). Group 1 consisted of children who had lost their brother or sister to cancer, and Groups 2 through 4 consisted of siblings of children who were receiving treatment for cancer and assigned to a group based on their siblings' cancer diagnosis. There were no other criteria for group assignment. Two groups ended up smaller than planned when two participants declined participation just before the meeting started.

Procedure

The study was carried out between January 2006 and April 2007, and was approved by the Regional Ethics Review Board in Göteborg. For practical reasons, two groups met in a room in the play therapy department at the hospital, and the other two groups met in a conference room at the pediatric oncology unit. The same moderator led all the sibling support groups. The moderator (first author) has a long history of working with support groups for children and adolescents. The participants in the four groups met three times. Each session lasted one-and-a-half hours, and all sessions were recorded on audio tape. The participants and the moderator sat around a table so everyone would feel he or she was in the center, not singled out and without too much focus on him or her.

The support groups started with a conversation circle in which everyone was able to express what he or she was experiencing at the time. Everyone was allowed to say something or answer a question without being interrupted. The moderator divided the time evenly between the participants, and let everyone have his or her turn in order. The siblings then introduced themselves to each other and then to the group. The participants wrote down their expectations of the first and future meetings. Siblings brought a photograph of their brother or sister (in treatment or deceased) and used it at the first meeting to help them talk openly about their brother or sister. A photo-language technique, using pictures to communicate in groups, has been described earlier (Akeret, 2000; Lepp, Zorn, Duffy, & Dickson, 2003). When unlike motives of pictures are placed on a table or floor, the participants can choose one or more and tell about the situation. These images provide an avenue for sharing feelings, thoughts, and experiences, connecting different events in the photograph with their story telling.

At the second and third group meetings, the moderator asked how the siblings had been since their last meeting and if there was anything they would like to discuss further. At the second group meeting, siblings also selected pictures from over 100 different settings to capture a feeling or view of a memory they had encountered in their situation. Pictures in different settings have been used as a therapy tool for children and adolescents before, and they have helped reduce worry and depres-

sion levels, improve self-esteem, increase social activity, and raise expectations of health (Reynolds, Nabors, & Quinlan 2000).

At the third group meeting, the siblings were asked to paint a picture using watercolors in three steps: background, setting, and finally, adding a few words. While the colors were drying, the siblings talked about what they had painted. When the pictures were finished, the siblings put them up on the wall and described their pictures to the group. Painting as a way to describe feelings has been assessed before (Rollins, 1990; Rollins & Riccio, 2002). Paintings in a group setting have been shown to release emotions of melancholy and aggravation, as well as facilitate the expression of emotions when a child is grieving over the death of a parent or grandparent (Nabors et al., 2004).

All support group meetings ended with the moderator reiterating what had been said and the participants being given the chance to express what they had experienced during their meeting. Time was set aside after each support group meeting for individual consultations for the participants if needed. If any sibling felt the support group meetings or evaluation interviews were too difficult or uncomfortable, the opportunity to see a social worker or psychologist at the hospital was offered. None of the siblings requested support from the social worker/psychologist or modera-

Table 2.
Evaluation Questions

1. What has the group given you?
2. What have you given the group?
3. How did you feel about having a leader direct the group?
4. Do you think the moderator conducted the meetings well?
5. How did you feel about writing down your expectations?
6. How did it feel to present another participant in the group?
7. How did it feel to show a picture of your sibling?
8. What was it like to choose a picture from more than a 100 to capture a feeling or an experience?
9. How did you like painting with watercolors?
10. How did you feel when you were asked if there was anything from the last meeting that you would like to talk more about?
11. How did you like talking about your experiences after each group interview?
12. Did you miss anything?
13. Is there something you want to add?
14. Do you have any questions?

tor after the conversational support group or the evaluation interview.

Data Collection

The siblings' experiences of participating in the support groups were evaluated through individual interviews two weeks after the last group meeting in the room that had been used for the meetings of Groups 1 and 2. For Groups 3 and 4, in which participants were further from the hospital, telephone interviews were conducted. The interviews consisted of 14 questions (see Table 2), with additional follow-up questions ("How did you feel then?" "Can you tell more?" "What were you thinking?"). The interviews lasted 15 to 30 minutes. All interviews were recorded on audio-tape and transcribed verbatim. Approximately two weeks after the individual interviews, the moderator telephoned the siblings to see how they were doing and if they had any thoughts or wanted to add anything. Two experienced nurses who had not been involved in the therapeutic support group conducted the interviews, so the siblings would feel free to express their opinions about the support meetings.

Data Analysis

The research team evaluated the follow-up interviews with the siblings using qualitative content analysis to draw a systematic conclusion from the words expressed in the text and

Table 3.
Categories and Subcategories

Category	Subcategory
Belonging to a group	Talking about your situation.
	It helped to hear what others were feeling.
	Recognizing yourself in what others were saying.
	Finding the inner strength to carry on.
Important as a member of the group	Getting to know each other.
	Allowed to talk or remain quiet.
	It was an advantage that the group members were of different ages.
Therapeutic support helped siblings recall and understand their memories	The tools used gave a form to the feeling and brought back memories.
	It was good to end the meetings with closure.
	It was good to continue the discussions from the previous meeting.

extract the message (Krippendorff 2004). The interview text was analyzed by three of the authors, first individually and then together in discussion, until a consensus was reached.

The interview text, which was transcribed verbatim, were read to get a feel as a whole and help find the core meaning of what was said. Units of meaning were identified from the text as suitable representations corresponding to the aim. The text was condensed, and representative units were coded with a designation and sorted into subcategories and categories (see Table 3). For the purpose of trustworthiness, the analysis process is described according to each step indicated by the method, with example quotations (Cutcliffe & McKenna 1999; Krippendorff, 2004).

Results

The interview text of the 15 siblings was analyzed after the siblings had participated in one of the four support groups. The text was divided into 10 subcategories, which constituted three categories (see Table 3). The categories and subcategories are described below.

Belonging to a Group

Talking about your situation. The siblings welcomed the opportunity to express their thoughts in words and of being able to say how they felt from their own perspective. They also thought it felt good to talk about their brother or sister and for their story to

be acknowledged. The older participants were better able to express their thoughts and feelings in words, which made it easier for the younger participants to put words to their feelings. "To not feel so lonely. It was good to be able to talk, seriously good." "The older participants were better with words and sentences." "They said what I wanted to say, and that was good."

The siblings wished they had been in a sibling support group earlier to talk about their feelings: "One thing I regret is that in the beginning, when my brother passed away, I kept all my emotions inside." "When it really should have been talked about much sooner."

It helped to hear what others were feeling. It was important to hear how the other siblings in the group had felt when they told their story. Above all, they felt it was very important to know one can experience happiness, and you can and are allowed to be happy even though you are going through a difficult time. "It was good to hear how others felt." "Even though he died, you don't have to be sad your whole life; you can be happy."

Recognizing yourself in what others were saying. When they met the other siblings in the group, there was a feeling of belonging. Friends and classmates are important, but they do not understand how you feel even though you sometimes told them the situation. They also thought children getting cancer was so rare that it is not something you talk about with anyone.

The brothers and sisters discovered they were not alone in their thoughts and emotions because there were others in the same situation. "Meet other siblings because the ones you know don't realize, they haven't gone through these feelings." "It helped me to understand that there were others in the same situation." "There are other people who feel like I do and who are in my situation, that was a relief." "And also fun."

Finding the inner strength to carry on. The siblings who were listening to the other siblings' stories expressed the individual who told the story was very special to the sick brother or sister and his or her family. The life-changing events expressed showed insight and inner strength conveyed to others during support conversations. After each session in the group, it became easier for the siblings to gain some insight into their own feelings and understand their role with the sick child. The siblings gained support and strength from the sense of community and from the understanding of others. "Hearing the statements from the others was good, for example, laughter and joy." "It's easier to be with N now after, easier to understand, know how to deal with it." "It's such a relief that there is actually someone who understands. You can tell your friends, but they can never say, 'I understand.'"

Important as a Member of the Group

Getting to know each other. To take the focus off the individual, the siblings presented each other to the group, which most of them thought was nice. They got to know each other through listening and reasoning. "It's always easier to talk about someone else." "It's about the other person, although it was me talking."

Allowed to talk or remain quiet. None of the siblings felt forced to say anything when it was his or her turn. If the siblings did not want to say anything, they did not have to, and if they wanted to tell a story, they could. "I didn't feel stressed, and I got to say what I wanted."

It was an advantage that the group members were of different ages. The groups consisted of siblings of different ages. Some siblings were young, but the participants did not consider this to be a problem. The difference in ages gave the siblings an opportunity to see different ways of experiencing and reacting to their situation. This was very educational for the group. "It doesn't depend on how

old you look." "When somebody has experienced something like this, you act older." "I think the ages in the group were good; you noticed that everybody is thinking differently, yet still the same. That was good."

Therapeutic Support Helped Siblings Recall and Understand Their Memories

The tools used gave a form to the feelings and brought back memories. Selecting a photo, the painting, and choosing a picture were all viewed as helpful. Regarding *selecting a photo*, siblings thought it was easy yet difficult to choose a photo. Seeing and showing pictures of their brother or sister made it easier to understand and give an actual form to the feelings. "You didn't know whether to take a photo of him when he was sick or not sick, but I thought I'd take one when he was happy." "You know what they look like, so it's much easier."

About *the painting*, siblings described their different feelings using many colors. They explained why they had chosen a particular color. They thought painting with watercolors was fun, and it was never a problem to choose the setting for their paintings. The last step of their watercolor project was to relate one or more words to what had been painted. This allowed the siblings to write about their emotions (for example, expressing their love and worries through their painting). "A red background. Well, I thought of a color for love, and it's also my favorite color. I thought of the love for N and the love for those close and dear to me too." "It was pretty fun to paint with watercolors. I knew what I should paint – when he and I played football. We did it when he was healthy or felt well; that memory was the strongest." "There [were] anxiety and feelings."

When *choosing a picture*, siblings said the settings of the pictures reminded them of what they had shared and what their brother or sister liked. They felt it was very meaningful to remember those special times. "I saw my pictures almost immediately: Ahlgren's candy cars [small, marshmallow, car-shaped candy available in Sweden] that he liked to eat and then a dog because he had just picked out a puppy." "Those were the two that were closest to me or to him and described him most. Ah, maybe I would have liked one of those pictures where both siblings were hugging each other." "Like the love between a sister and brother."

It was good to end the meetings with closure. The conclusion helped the siblings, who deduced what had been said and helped them develop a structure to remember what they had talked about in the group. The conclusion helped them put some thought into it afterwards and to reflect on what they had been through. It also helped them tell their parents if they wanted to do so after they arrived home. It also felt good to hear the other group members' closure. "Suddenly there is nothing. It's not even worth it if you don't think about it a little after it has happened." "Good, then you know you didn't miss anything and not until then can you start your next project."

It was good to continue the discussions from the previous meeting. At the second and third meetings, the siblings were asked if they had thought about anything that had been discussed at the previous meeting or if they had not finished some of their reflections. The siblings thought it felt good to have the opportunity to talk if they needed it and the ability to compare what they had experienced at the other meetings. "It was very good to do that, to compare how it was with other meetings. I thought that was very good."

Discussion

This study looked at descriptions by 15 siblings in a therapeutic support group when their brother or sister was going through treatment or they had lost their brother or sister to cancer. A qualitative descriptive method was used, with the siblings expressing their own experiences of therapeutic support groups (Taylor & Bogdan, 1984; 1998). These were evaluated with individual structured interviews (see Table 2). The therapeutic support group arrangement can be compared with Morgan's (1993) focus group method, which used a conversation leader who was knowledgeable on the subject. The moderator who held the group meetings had a clinical background working with children and teenagers, which added to the credibility of the study. Surprisingly, as many as 14 families declined to participate in the study when asked. Being included in a study might feel threatening in this vulnerable situation. A few groups became smaller than planned for different reasons. A few siblings and/or parents refused to participate, and a few siblings regretted having given their informed consent just before the meeting started. One thing that could have been done

differently would have been to allow more time between the diagnosis/death of a child and the initial group meeting. Because patients are in shock immediately following the diagnosis of cancer or the death of a child, they may find it difficult and even overwhelming to decide on participation in a research study. This may be even more pronounced in a study regarding siblings because parents may worry on how they will cope.

In this study of siblings' experiences of a therapeutic support group, only the siblings participated. It is significant that the information is from the participants themselves and not from proxies, such as parents, (Nabors et al., 2004).

Belonging to a Group

Being a sibling of a child with cancer has been described as a distressing situation with feelings of anxiety and anger (Dellve, Cernerud, & Hallberg, 2000; Lehna, 1998), as well as fear of a relapse and possible death of the brother or sister (Barrera et al., 2002; Koch-Hatten, 1986; Lehna, 1998; Martinsson, Gilliss, Colaizzo, Freeman, & Bossart, 1990; Walker, 1988). The distress can lead to worries, loneliness, and negative behavior (Hamama, Ronen, & Feigin, 2000). A negative effect on quality of life has also been described (Houtzager, Grootenhuis, Caron, & Last, 2004; Houtzager, Grootenhuis, Hoekstra-Webers, Caron, & Last, 2003). In this study, the siblings expressed the value of belonging to a group of other siblings. Through the group, the siblings were able to meet other siblings who shared the same experiences and who were going through the same things or were dealing with a brother or sister who was being treated for or had died from cancer.

In the groups, the siblings were able to tell their own stories and listen to others who had gone through the same events, and found it was reassuring they were not alone. According to Murray (1998), children who have a sibling with cancer need someone to talk to, someone who understands, and a room where they can speak freely without having to defend what they express. In their everyday life, siblings often keep their thoughts and emotions to themselves because they did not have anyone to share them with (Cairns, Clark, Smith, & Lansky, 1979). For the younger children in this study, it made particular sense to hear the older siblings' stories. It helped them understand and express themselves better. Sloper (2000)

Children and youths who have participated in support groups have reduced their stress and anxiety and gained a preparedness to deal with their emotional reactions.

reported siblings who were able to express their own emotions achieved greater recognition and self-esteem. Sharing in the others' stories helped siblings put words to difficult and conflicting emotions. Several authors have also showed it is very important for siblings to be able to express their own thoughts (Murray, 1998, 2002; Scott-Findlay & Chalmers, 2001; Sloper, 2000; Woodgate, 2001). The siblings in this study were able to recognize themselves in the other siblings' stories. They shared the same emotions and behavior, and felt a connection. After meeting other siblings in the same situation, the siblings' social competence increased, and their feeling of isolation decreased. This has also been described by Creed and colleagues (2001) and Sidhu et al., (2006). Being acknowledged by the group gave the siblings strength to carry on.

Important as a Member Of a Group

In this study, the siblings felt they were important members of the group. Some even described the group as the only place where they felt comfortable and fitted in with their experiences. The support groups served a purpose for the participating siblings because siblings often feel forgotten and unimportant (Havermans & Eiser 1994; Iles, 1979; Murray 2002; Rollins 1990; Sloper 2000). In the groups, the siblings felt it was permissible to talk and remain quiet. If they had something to say, they felt they could speak without being interrupted. The groups included a range of ages, which the siblings appreciated. The siblings described themselves as comfortable in the group and as being able to tell their own story, including happiness and laughter, and they realized no one expected them to be sad all the time. According to the attachment theory by Ainsworth, 1991, a special attachment, which has nothing to do with age, appears to form rapidly in the sense of group membership. The siblings also gained a better understanding of their sick brother or sister and how they should act when they were together. The siblings developed a cer-

tain comfort level even though they did not know each other before, and they were able to give each other support and reassurance.

It has been reported elsewhere that siblings of children with cancer ask for support from several sources, such as from their family, staff, and friends (Freeman et al. 2003; Havermans & Eiser, 1994; Murray, 1998, 2002; Sloper 2000; von Essen & Enskär, 2003). Further, parents of children with cancer hardly recognize the siblings' needs for support (Ballard, 2004). Knowing the very positive effects pointed out by the siblings in this study, it is surprising that siblings are rarely offered these kinds of therapeutic support groups. In this study, the participants said they wished they had been offered the opportunity to participate in a group earlier, and none of the siblings regretted his or her participation. All siblings who started in the groups made all the sessions.

Children and youths who have participated in support groups have reduced their stress and anxiety and gained a preparedness to deal with their emotional reactions (Williams, Chaloner, Bean, & Tyler 1998). Houtzager et al. (2001) found siblings of children with cancer experience less anxiety after participating in a support group. These results are congruent with those of several support groups for bereaved parents of children who have died from cancer (DeCinque et al., 2006). The same method (focus group-oriented supervision) has also been used for nurses in intensive care and been proven to increase the insight of the nurses into the needs of the family members and their own role (Lantz & Severinsson, 2001).

Therapeutic Support Helped Siblings Recall and Understand Their Memories

The technique of ending each meeting with closure helped the siblings develop a structure to remember what they had talked about, put some thought into it afterwards, reflect on it, and helped them tell their parents if they wanted to know. It also allowed them to continue discussions from the previous meeting.

In the process of using different "tools," the siblings had to choose photographs and setting pictures to see, show, and paint, and this helped them understand and express their emotions and resurfaced memories. Words can sometimes be hard to find or may feel intimidating, so these tools helped them dare to express what they were going through. The pictures and art in this study offered support to the siblings, and helped them reflect on and bring out both the negative and the positive emotions of their memories, something that has previously proven to be beneficial to siblings (Akeret, 2000; Boronska, 2008; Lepp et al., 2003; Nabors et al., 2004; Rollins, 1990; Rollins & Riccio, 2002).

Implications for Nursing Practice and Future Research

A therapeutic support group for siblings of children with cancer should be included in the care of the family and be offered several times during and after the treatment to help siblings through their brother's or sister's childhood cancer. A support group for siblings can make it easier for them to deal with and understand their feelings. Support groups can also be used in other situations when there is a seriously ill child in the family. More intervention studies will need to be conducted in the future to help siblings talk about their experiences.

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