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Children's Experiences of Participation in a Family Support Program When Their Parent Has Incurable Cancer

KEY WORDS

Cancer

Children

Coping

Family support program

Nursing

Parents

For a child, facing the imminent death of a parent is a highly stressful situation. This study assessed a preventive support program for children aged between 5 and 18 years and their families when a mother or father has an incurable form of cancer. We chose a family-based approach to reduce risk factors and enhance protective factors by increasing positive interactions between parents and children and by increasing their mutual understanding of the illness and its family impact. In this article, we focus especially on the children's experiences of how the Family Support Program met their needs and supported their coping. The qualitative study involved collecting descriptive data via in-depth interviews with children of cancer patients in palliative care after participation in the Family Support Program. The program helped the children to feel more secure; increased their knowledge and understanding; helped them become aware of their own role, their family's strengths, and whom they could approach for help; and helped them realize that it was good and helpful to talk about the illness situation. They needed to talk in private without having to think about other family members' reactions, but they also needed to be in dialogue with other family members.

Children's reactions and coping when 1 of their parents has cancer merit greater attention from health professionals. The terminal phase of this illness is

particularly stressful,¹ and studies have shown that children at this time struggle with fear, sorrow, anxiety, anger, withdrawal, and feelings of guilt. Judging children's reactions can

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The Foundation for Health and Rehabilitation sponsored the project activities in the hospitals. Oslo University College sponsored the time needed to undertake the evaluation research. Ullevaal University Hospital, Akershus University Hospital, and Innlandet Hospital helped to create and implement the intervention program.

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Accepted for publication May 30, 2008.

be difficult because they react in different ways and deal with the challenges of the situation differently.²⁻⁵ In particular, unstable illness conditions and treatments such as surgery and chemotherapy upset children and make it hard for them to cope with the situation.^{2,4}

Research has highlighted age differences in children's reactions to parental cancer.^{1,6} Children aged between 6 and 8 years often misunderstand the cause and effect of illness and treatment, are highly emotional, and have difficulty containing emotions, whereas older children aged between 9 and 11 years understand causes and treatment but often avoid their own strong emotions. In addition, 9- to 11-year-olds are capable of expressing sadness because they seem to understand the grim prospects facing their parent(s) and themselves. The adolescent group between 12 and 18 years often experience conflicts between autonomy and attachment to the ill parent.^{1,6}

We know that when a parent has cancer, both parents struggle to meet their child-rearing responsibilities by trying to provide practical and emotional support and comfort for their children.⁷⁻¹⁰ For a child, facing the imminent death of a parent is a highly stressful situation. Research suggests that parental cancer places children at risk of adverse psychosocial consequences.^{1,11} However, there are both risk and protective factors that mediate the child's coping. Visser et al¹² concluded in a review that communication is important for children's psychological adjustment. In one study, high anxiety scores among adolescents were linked to their inability to discuss the illness with their parents.⁴ Rosenheim and Reicher¹³ found that anxiety levels for children who had been informed about their parent's illness were lower than for children who had not been informed.

Bereavement research shows that for children and adolescents, parental support is the most important protective factor in helping prevent psychosocial problems. The next most important factors are knowledge and understanding of events.^{11,14} It is thus vital to provide supportive interventions for children during the different stages of a parent's terminal illness, with a particular focus on the significant moderating and mediating variables that will help them best deal with their difficult situation.¹

In one study that reviewed interventions to improve communication with children and adolescents about a family member's cancer, evidence suggested that supportive programs such as structured group interventions might lead to improvements in knowledge and understanding that help children with coping, anxiety, adjustment, and well-being.¹⁵

Beardslee et al¹⁶ found that specifically designed, preventive, family-centered interventions that are manual based and relatively brief have long-standing positive effects in helping families manage problems related to parental illness. They conducted a longitudinal, primary prevention study of relatively healthy children who were at risk of psychopathology because of their parents' mood disorders. This study demonstrated significant reductions in risk factors and increases in protective factors for nearly 100 families over a long time interval. These models of family-centered approaches to

helping children cope served as the basis for the development of our program. It is not sufficient, however, to merely develop and implement family-based interventions. If we are to be genuinely critical, reflective, and understanding in relation to if and how such interventions work and how they are experienced by families, then it is crucial to incorporate evaluation into the process. This article reports such an evaluation of children's experiences.

■ The "Family Talks in Cancer Care" Program (Family Support Program)

Aims, Purpose, and Philosophy of the Program

This study assessed a preventive support program for children aged between 5 and 18 years and their families when a mother or father has an incurable form of cancer.

The purpose of the family program for children was to prevent psychosocial problems and to promote coping by:

- helping the family talk about the illness and related subjects;
- giving children knowledge and security about both the illness and the impact created by the illness situation on their daily living; and
- helping the family plan for the future.

We chose a family-based approach to reduce risk factors and enhance protective factors by increasing positive interactions between parents and children and by increasing their mutual understanding of the illness and its family impact.¹⁶⁻¹⁸

The coping theory of Libo and Griffith¹⁹ for children was used in the development of the program, in the final stage of analysis in the evaluation study, and in the presentation of results from the study. Libo and Griffith¹⁹ proposed a coping theory for children based on 2 central components: the experience of belonging and competence as important elements for children's ability to cope in difficult situations. Belonging comprises elements of confidence, predictability, confirmation, and association within the family and support from social networks. Competence comprises knowledge about the illness and the subsequent reactions, helpfulness and utility, being able to give and accept responsibility, and being able to meet and cope with hardship.¹⁹⁻²¹ The program was child centered and set out in a manual that described in detail the background, theories, and goals of the program. The manual also detailed each meeting with the family, detailing how to meet specific problems, how to increase communication within the family, and how to improve the children's understanding of illness. Various strategies were developed and implemented in the different meetings with the families, including conversation techniques, books, and different expressive techniques such as drawing and writing. The program used mapping of the children's social network as one technique to assess the support that children gained. We chose an

approach based on the families' strengths because it is helpful to use identified strengths as an impetus for further positive growth and development.²² The program incorporated a family task where the family members had to tell each other about strengths and positive skills. Books were in use to improve children's understanding of illness and their own reactions to the situation.

Approach and Operation of the Program

Three Norwegian hospitals in the eastern part of Norway created and used the Family Support Program from October 2004 to August 2006. Six health workers (4 nurses, a sociologist, and an art therapist) worked with the project leader (K.B.) involved in developing the program. The 6 health workers, who were all trained and experienced in cancer care, carried out the support program, 2 in each hospital. Of the 3 hospitals involved, 2 were university hospitals with palliative care units and 1 was a regional hospital with a cancer ward. Before the program, the 3 hospitals had shown their interest in developing support services for children when their parent had cancer. Program staff completed a mandatory training program in advance, with an 8-day course developed by the project leader, to improve their communication skills with children and families and to become fully conversant with the purpose and processes of the program.

The Family Support Program comprised 5 meetings conducted over 5 or 6 weeks (Table 1).



**Table 1 • Family Support Program—
The Meetings**

1. Family meeting. This was a short meeting involving presentation of the support program and introduction of the project workers.
2. Parents' meeting. Here, the project workers talked with parents together about their experiences with parenting and family coping during the illness situation.
3. Children's meetings. A project worker talked with each child in the family about his/her experiences during the illness situation and about changes the illness had created in his/her family and with himself/herself. The children were asked to draw a social network map and to point out to whom in particular they talked about the illness situation. Younger children were asked to draw freely during the talk. They were asked if they had questions about the illness or about the treatment or changes in their family situation. The project workers provided the children with age-appropriate information about normal reactions and how best to cope with these. They also planned what to talk about in the next 2 family meetings.
4. Family meeting. This was a meeting where the concerns of both children and parents were discussed and family strengths were discussed and assessed.
5. Family meeting. We focused here on how to face the future using the family's strengths and on where to seek additional help or support if needed.

■ Study Approach and Methods

Purpose of the Study

It is not sufficient to identify service needs and devise programs or interventions to meet these needs. A further vital stage is to assess and evaluate the interventions to determine if and how they made a difference. The purpose of this study was thus to assess whether the Family Support Program was achieving its aims. This was determined by exploring the impact of the program on participants' psychosocial problems and coping. In this article, we focus particularly on the children's experiences of how the program met their needs and supported their coping. A related article will present parents' experiences and perceptions of the program.

Study Design

The qualitative design involved collecting descriptive data during in-depth, open-ended interviews with participants in the Family Support Program, focusing on experiences with the program. The collection and analysis of data followed Kvale's²³ guidelines for qualitative research, which incorporate a phenomenological-hermeneutical mode of understanding. Kvale²³ states that the qualitative research interview attempts to understand the world from the participant's perspective in order to uncover the meaning of people's experiences and to reveal a clearer understanding of their lived world. We therefore sought to describe and understand the experiences of the children who were living with parental terminal cancer and who took part in the Family Support Program.

Qualitative interviews offered the children the opportunity to express themselves freely while also assuring them that they had the researcher's support should they wish to end the interview at any time.²⁴ Interviews allowed the participants to convey to others their situation from their own perspective and in their own words.²³

Recruitment and Characteristics of the Study Sample

We planned to conduct in-depth interviews with 4 to 6 families that had completed the whole Family Support Program and would stop recruitment to the research when saturation was gained. Patients with incurable cancer who had at least 1 child aged between 5 and 18 years were invited to participate in the program. They were provided with verbal and written information (to take home and discuss with their family). Eleven patients were invited to take part in the Family Support Program; 1 patient declined to participate, and 10 patients agreed to participate, but of those, 4 patients were unable to complete the program because of the severity and progress of their illness. Six patients who fulfilled the study criteria were included in the study. Parents discussed the study and their possible involvement with their children, and subsequently, all of the children in the 6 families chose to

participate. The 12 children were aged between 6 and 16 years, with a mean age of 9 years. A total of 8 girls and 4 boys were included in the study.

For 5 of the children, their mother was ill, and for 7, it was their father. In 3 families, comprising 5 children, the parents were divorced and the children lived together with 1 of their parents and the parent's new partner. In 1 of the divorced families, the parent with whom the child lived was dying and the child was to move to live with the other parent.

Parents reported that 3 of the children received, for a short period after the onset of their parent's illness, support from the child and adolescent psychiatric department, 1 because of aggressive behavior in school, 1 because of psychosomatic reactions, and 1 because of fear and sleeping disturbances. The school nurse supported these 3 children plus one other over a long period.

Data Collection

All children and adolescents were interviewed once up to 6 weeks after the Family Support Program concluded. K.B. conducted all the interviews because she is a nurse and is trained and experienced in talking with children in difficult life situations. Interviews were conducted either in the hospital or in the children's home. The duration of the interviews ranged from 20 to 90 minutes. Younger children could draw during the interviews to help them concentrate and to give them the opportunity to express themselves in different ways.

Data Analysis

An open, exploratory approach was taken to the data analysis. Following Kvale's²³ guidelines, analyses occurred within 3 different contexts: self-understanding, common sense, and theory. K.B. conducted the data analysis. In the first context, the interview transcripts were read and summarized into a condensed form of the participants' understanding of their situation. One example can illustrate the process. From one child's long story about talking alone with the health worker in the program, the condensed form was "I feel better now that I have talked about it." All transcripts were then re-read and coded, after which categories were assigned using descriptive terminology. The descriptive category in our example was "Relieved after telling." Next, questions were asked of the situation: What are children telling us about their situation and is the Family Support Program helping with this? Main themes were then drawn out and constructed for "common sense understanding"; continuing with the foregoing example, the identified theme was "Talking freely helps." Subsequently, all themes from all participants were synthesized. Finally, these main themes were interpreted and discussed in light of the coping theory and research underlying the Family Support Program. Part of the coping theory in use is belonging, with the category confidence. "Confidence to talk about the illness situation" was the category for our example above. During the theoretical interpretation, the themes that form the basis for the presentation of findings in this article were created.

Ethical Issues and Approval

It is important to minimize the risk of harm or discomfort to participants in research. There are particular tensions between not placing children at risk in studies of new interventions and the need to generate knowledge regarding the impact of interventions with children.²⁵

Children should be informed about research in a way that makes it possible for them to give their consent.²⁶ We therefore prepared separate information sheets for children aged 6 to 7, 8 to 11, and 12 to 18 years. Children younger than 7 years gave verbal assent and those older than 7 years gave written assent to participate in the study. In addition, written informed consent was obtained from parents for their children's participation in the study.

Interviews with the children were conducted with only the interviewer and the child present, or with siblings or parents if the child felt insecure being alone. Eight children were interviewed alone, 2 were interviewed with a sibling present, and 2 were interviewed with their mother present. The nature of the study meant that sensitive questions were asked about potentially difficult and distressing topics—principally, the death of the child's parent. It was clearly important, therefore, that when questioning children, we were sensitive to what they tried to tell us and that we gave support or stopped the interview if the questions affected the child negatively.

The study was approved by the Regional Medical Ethics Committee in Norway and the Norwegian Data Register. Confidentiality of participants was maintained, and the interview tapes were stored in safe, locked environments. These were destroyed when the analysis was complete, in accordance with the guidelines of the Norwegian Data Register.

■ Results of the Study

The 2 prominent themes identified in the analysis were children's main concerns in the situation and children's experiences of taking part in the Family Support Program in relation to their coping with the situation. The coping theory for children that informed the project comprised the principal concepts of belonging and competence; results are presented with reference to these concepts.

Children's Main Concerns in Relation to the Illness Situation

FEAR THAT THE PARENT WOULD DIE

Children regularly thought about death in connection with cancer, and both the youngest and the oldest children in the study did this:

I did not know anything about cancer, only that it is dangerous and people die. At the start of the illness, I thought a lot about him dying. (Boy, 15 years)

During the parent's treatment periods, younger children often misunderstood the situation. One 6-year-old girl told us about a time when her father looked "deathlike," and after that, she was afraid he would die. Most of the children knew the parent would die of the illness sooner or later, even if they had not been told directly:

I was thinking, next time I come to visit him, he might not be here any more. (Girl, 12 years)

BEING UNABLE TO TALK WITH PARENTS ABOUT THE ILLNESS SITUATION

Children had questions to ask but had not dared to ask them. They thought that their questions would upset their parents and were thus reluctant to voice their questions or concerns. They wondered when death might actually occur and described how they would have liked to have a timeframe to prepare themselves for the loss and to know when they could start to live more normal lives again:

I did not dare to ask how long he could live and he did not say anything. (Girl, 12 years)

BEING SAD AND FRIGHTENED, SEEING THE CHANGES IN THE PARENT'S CONDITION

The illness changed the parent's energy and appearance, and children described how it was sad to see their parent deteriorate and change in this way:

My daddy weighed 120 kg before he became sick. After he was sick, he lost 60 kg and he did not have energy to do anything. It was sad. (Boy, 8 years)

Children described "scary situations" when their parent had an "attack" of some kind, had recently undergone surgery, or was in the hospital because of the severity of his/her symptoms. Younger children in particular often did not understand what had happened and experienced it as being unpleasant and uncomfortable:

I was a bit anxious about when we should visit (her father in the hospital). I said I don't want to come with you, but I changed my mind and went with my family. It was scary. I nearly vomited because of all the drains and the blood and everything. (Girl, 6 years)

HAVING FANTASIES AND FEARS ABOUT CANCER AS AN ILLNESS

Children had been told that cancer was not a contagious disease that you could catch from another person, but still, some of them were insecure and afraid. In one family, 2 close family members had cancer at the same time and the children wondered how this could happen if not by contagion. The younger children especially had difficulties in understanding the causes of cancer. They found it difficult to understand what they had been told about cancer cells and tended to

conflate or confuse this information with what they knew about other diseases. This made them afraid of "catching" the disease themselves. This child's account was illustrative:

I wish I could see the cancer, what the cancer bacteria look like. They are small bacteria that become big lumps. The brain says it is enough, but they will not listen. They only grow and grow all the time. Do you want me to draw how the cancer cells become big? But the medicines did not work on my mother's cancer cells. I think it is too late because they have become too big. Is it rare for children to have cancer? I don't want to get the disease from my mother. (Girl, 6 years)

Some children were afraid of "catching the disease genetically," especially if there were other genetic diseases in the family.

How Children Experienced the Family Support Program in Relation to the Coping Factor "Belonging"

CONFIDENCE TO TALK ABOUT THE ILLNESS SITUATION

Some of the children were sufficiently confident to talk to their parents about their insecurity and reactions to the illness situation, but others had problems talking freely with their parents or others in their close network. In particular, older children and adolescents had not told their parents about their problems. One said he had never liked to, another said it was to protect her parents because "they had enough problems on their own". For the children, it felt good to talk with someone outside the family:

I thought it was very good (to talk with the project worker). I have had periods where I have been sick (on verge of vomiting). I think it was because of the situation. I think it was because I had so much locked up and I did not want to talk with anyone about it. I don't like to talk about it. I don't want to talk to my parents. (Boy, 15 years)

The children said they felt better after talking to the project workers alone. They felt relieved:

I feel better now that I have talked about it. (Girl, 9 years)

The children also said that it was a bit scary to talk alone with one of the project workers because they had never met her before. They said that it was like that only initially. They soon came to know the project workers and felt they were helpful and nice:

I was a bit afraid. I do not like to talk with strangers. But she was nice. (Girl, 6 years)

Even if the children had talked a lot within the family, they said it was good to talk with someone outside the family who respected their wish not to tell others. Even the small children liked this.

PREDICTABILITY ABOUT THE ILLNESS SITUATION

Children who were not previously informed about the prognosis of the illness were relieved to be informed. Some of them said they would have liked to have a more exact time-frame so it would be easier to plan for the future. Children wanted more knowledge about the prognosis and if a cure was possible or not:

We talked about it the second time we were here (second family talk) and that he (her father) could never be cured. (Girl, 12 years)

Children said that there was a lack of information about the Family Support Program before it started, which had led to uncertainty and anxiety:

They (parents) had not told me much, so I was a bit anxious about what they expected from me. (Girl, 12 years).

TALKING ABOUT FAMILY STRENGTHS, CONFIRMATION, AND ASSOCIATION WITHIN THE FAMILY

The children liked the task of drawing their own networks map and pointed out with whom they could talk about the illness situation:

I was to mark out who I liked to talk to if I was sad. Mummy, daddy, my teacher, grandma, grandpa, and my siblings. (Girl, 9 years)

Children found it helpful that the project workers asked questions and helped them to express their concerns in the family talks. They were concerned about the illness situation:

We (the whole family in one of the family talks) talked about that I'm scared he (my father) is going to die. (Girl, 6 years)

Children found that openness in the family talks also made it easier to talk more openly when the family was alone:

After these meetings, things have changed. Now, we (the whole family) can talk openly about the illness situation. (Girl, 12 years)

The children wanted their lives to be as normal as possible despite the illness situation. They had asked in the program to undertake more of their usual activities and that their parents had accepted this. They liked the family task where they had to write and tell others in the family about their strengths and importance:

It was a task where we had to write. And I started. We said what was good about our family. My family is good. My brother is good to comfort me, my father is good to help all in the family, and my mother keeps the house clean. (Girl, 6 years)

The children realized that parents and siblings were glad to hear what they said about their strengths:

We wrote to each other about our strengths. I liked to do that. My siblings were glad about what I told them. (Boy, 11 years)

Siblings who had been together in the talk said that it held them back from talking about a difficult situation they did not want their sibling to know about:

My sister does not understand much about the situation in the family. She does not know about my parents' problems. I could not talk about it with her present. (Boy, 15 years)

INFORMATION SHARING WITH SOCIAL NETWORK ABOUT THE ILLNESS SITUATION

Children had thought a lot about how to tell friends of the illness situation. Those who had told their social network had experienced much support from teachers and classmates. Two of the children had not told their friends of their parent's illness and received help from the project workers to talk about the illness situation with their classmates. They were relieved after sharing the information with their friends:

It is good that my classmates know about it now. Then I don't have to be sad alone anymore. (Girl, 9 years).

How Children Experienced the Family Support Program in Relation to the Coping Factor Competence

INCREASED KNOWLEDGE ABOUT THE ILLNESS AND PROGNOSIS

Children wanted to know more about the illness and said that talking with the project workers had increased their knowledge. They also found it helpful to acquire more knowledge about their own reactions to the illness situation and what was expected of them:

She (the project worker) told me a lot about the illness and normal reactions when you have a parent with cancer. I wanted to know more. (Girl, 12 years)

BEING IMPORTANT AND "VALUABLE" IN THE FAMILY

Children valued having the confirmation that they were important to their family and that their parents appreciated that they were helpful and nice:

My father said I was very caring. I liked to hear that. (Girl, 12 years)

Children were encouraged to use the strengths they had talked about in the family task to do something memorable with their parent. In one family, it was to keep up the good contact with each other even if they lived separately; in another family, it was to make memory books for all the children. In yet another family, it was to create music together:

They told me I was good at playing the piano. I have inherited it (the ability) from my father, so now, we are going to play together and make a CD. (Boy, 8 years)

CONFRONTING AND COPING WITH THEIR OWN FEAR AND OTHER REACTIONS TO THE ILLNESS SITUATION

Children talked about their reactions to their parent's illness. Some had trouble understanding their own reactions, such as psychosomatic episodes and anger. The children and adolescents talked about situations when they had been scared in relation to the illness. Some said that their parents had recognized their anxiety, but others had kept it to themselves. Children had different ways of coping with their thoughts about their parent's incurable cancer. They spoke about how they avoided thinking about the illness situation and their fear of their parent dying because it was so painful:

Mostly afraid. I do not want to think about it, I want to have fun. If I think about it I start to do something that takes the thoughts away. (Boy, 8 years)

Children borrowed books from the project workers about how to tolerate and cope with anger, anxiety, and sorrow. They also talked with the workers about what to do when they became angry, afraid, or sad. They found this helpful and said that it lessened their sad feelings and other reactions. The project workers also provided examples of how to manage anger and anxiety.

We borrowed 2 books. The books said we were allowed (to be sad and angry). The books were good. You are not allowed to hit someone even if you are angry. I did it before, but less now. (Girl, 6 years)

■ Discussion

The goal of the Family Support Program was to prevent psychosocial problems and promote coping. According to the findings of our study, the children had reactions to their parent's illness that affected their daily living, such as anxiety about the death of a parent, anger and aggression against others, and sleeping problems due to anxiety. These findings support those of several other studies.^{1,11} Children were afraid and insecure about changes in the ill parent's condition and dying and the possibility of getting the disease themselves. They said that their problems were related to the severity of the illness situation. Other studies have reached the same conclusions.^{4,5,27}

To promote coping, the Family Support Program worked through 3 avenues: supporting the family to talk about the illness and related topics; giving the children knowledge, security, and help; and supporting the family plan for the future.

In this discussion, we highlight the interaction between children, parents, and health workers that the program created and the importance of age-appropriate information and understanding. Most of the children in our study experienced the situation as unpleasant, and they had questions that were of great importance to them but which they dared not ask their parents. The children's confidence with the project workers was important. They said that they felt better after talking with the workers. To share a frightening

situation with someone who listens and understands is helpful in itself.^{11,28,29} The most important feature was that the project workers helped children raise difficult questions with their parents and opened a pathway to open communication in the family about the illness situation.^{3,16-18}

The project workers' knowledge was also important. Children said that it was good to talk freely about the situation in the family and have the opportunity to put questions to someone who knew the illness and what it was like to be in a family where one parent has cancer. Forrest et al⁴ and Barnes et al^{30,31} also concluded that children and parents both want health professionals to talk with children about a parent's cancer.

Children in our study were proud of their family. They also wanted to be helpful and "good," and being told in front of the whole family that they were helpful and good was important to them. In the resilience theory of Libo and Griffith,¹⁹ children's need to be important and helpful to their family is stressed. Some of the older children found it difficult to talk about personal problems in front of younger siblings, and a meeting alone with parents and project workers would possibly have been better for these children to address their worries and questions.

The Family Support Program, with its 4 meetings, enabled a process to commence within the families. However, it was also important to consider how this process should be continued. In our case, the parents were encouraged to follow up the open communication in the family and were offered the opportunity to contact the hospitals involved at any time necessary. Christ and Christ¹ also suggest that communication can be viewed as a process with careful disclosure of information over time, creating a pathway of open communication and trust for children.

Children's understanding of the illness situation was dependent on their age group; most of the children in our study wanted more information about their parent's condition. In one study,¹² different age groups of children expressed different needs for information. Forrest et al⁴ found in their study that older children (≥ 10 years) wanted direct contact with health professionals in cancer care so they could learn more about their own parent's treatment regimen and prognosis. It is easy to misunderstand information about the biology of the cancer cells and cellular actions of chemotherapeutic agents, as a book for the Norwegian Cancer Society explains.³² Forrest et al⁴ found in their study that cellular information about cancer did not support good understanding for small children. It is important to inform children appropriately for their age about cancer to prevent misunderstanding and unnecessary fear. Myths about cancer still exist, and children hear them from family and friends and at school.³³ It is important that someone with authority explains what is actually known about cancer.

Children's knowledge about personal reactions and good coping strategies were strengthened through the program. As Lewis et al⁶ have shown, children's reactions to cancer differ with age. It is hard for small children to understand that their reactions are related to the illness situation. Children in our

study found some of their reactions to be unpleasant and were willing to try new coping strategies to feel better. They also realized that they were allowed to have a range of feelings.

Our study showed that predictability was extremely important for children in the illness situation. Children wanted to be informed about life expectancies and what would happen to them and their family in the future. Those who were informed about the incurable cancer situation through the program were relieved and felt it easier to talk to their family about the situation afterward. Still, they felt it hard to think about the parent's death, and at times, they avoided thinking about it.

Our program used children's strengths to involve them in the ill parent's last stage of life and to create positive memories. Bad memories and guilt from the illness situation can be hard to handle for children after the death of a parent and can lead to complicated grief, whereas good memories make the grief less complicated.^{28,29} Importantly, we talked to the children alone to find out what they struggled with and how they coped with their situations. We supported them in using time for normal activities despite the incurable illness situation. At this time, children can find it hard to express their wishes about pursuing their own interests because they feel that it is selfish to do so.

The main aim of our Family Support Program was for children to strengthen their coping. According to the coping theory in use, strengthening belonging and competence in a difficult situation for children gives them self-esteem and strength to face the future. This study echoes many of the findings of similar research undertaken internationally. In the research of Beardslee et al,¹⁶ 2 different interventions showed similar results. Other studies in cancer care have shown that parents wanted the kinds of help and support that our Family Support Program has provided.^{7,10,30,34} The evaluation of Thastrum et al³⁵ of their family counseling program showed similar outcomes to those of our children's program.

Rigor and Trustworthiness of the Study

Qualitative research is best judged not by the criteria of quantitative methodology such as statistical reliability and validity but by rigor and trustworthiness.³⁶ To ensure these, one fellow researcher, S.H., also analyzed the interviews of two of the families and critiqued and questioned the main presentation of the findings in this article. In qualitative research, reflexivity and preconceptions will influence the study and have to be defined, as we have done in this study.³⁷

This was a small, qualitative study conducted with children of different age groups from 6 families from 3 different areas in the eastern part of Norway. Although we would not attempt to generalize from a small study, we suggest that our sample of children will be very similar to many other children facing a similar situation. Four of the children in our study had reactions directly influenced by the illness situation for which they received psychosocial treatment. These 4 children experienced severe changes in their daily living because of their parent's illness situation. In Worden's¹¹ study, 30% of the

children developed psychosocial problems after the death of 1 of their parents. Worden¹¹ also showed that when children developed problems, these normally persisted for a long period and were often connected to the parent's difficulties in coping with the situation.

Children of divorced parents normally experience more risk factors, perhaps because of higher conflict levels between their parents and difficult custodial or living arrangements. However, they also develop strategies that enhance their resilience.³⁸ Children of divorced parents in our study had parents who did cooperate. One of the children in our study was prepared to move to live with her father after her mother's death. Children with divorced parents face other problems. The Family Support Program should take the special circumstances of children of separated and divorced parents into account and provide the particular support that they need.

All studies have limitations, and we acknowledge that this is a small-scale evaluation. It was not possible to explore meaningful differences in relation to, for example, the sex, socioeconomic status, or age of the children or the sex of the ill parent. It would strengthen future evaluation if the program was made available in other centers and areas and if a longitudinal element was introduced in a follow-up study of the children who participated (Table 2).

Conclusion

Children who have a parent with incurable cancer need more than simple information about the illness situation. They need help to understand themselves and to learn how to deal with a range of difficult and confusing feelings, thoughts, and reactions. Support from parents is essential, but children also need support from health professionals that is sensitive and developmentally and age appropriate.

The Family Support Program was conducted in line with these guiding principles. The children's accounts of their understandings and experiences of participating in this program suggest that such a child-centered approach, which builds on the strengths and qualities of both families and children, can make an important positive contribution to their well-being at this most traumatic time in their lives.

Table 2 • Recommendations for Practice

- Help parents to understand their children's needs and how best to support them from a coping perspective by focusing on family strengths and supporting family togetherness.
- Give children opportunities to talk with a health professional about their experiences in relation to their parent's illness. Focus on protective factors mediating coping. Use drawing and writing techniques with children 10 years or younger.
- Give age-appropriate information about the disease, treatment, reactions, and coping. Use books and films.

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