Children’s experiences of the family talk intervention when a parent is cared for in palliative home care—A feasibility study

Rakel Eklund, Li Jalmse, Ulrika Kreicbergs, Anette Alvariz, and Malin Lövgren

Department of Health Care Sciences, Palliative Research Centre, Ersta Sköndal Bröck University College, Stockholm, Sweden; Department of Neuroscience, National Centre for Disaster Psychiatry, Uppsala University, Uppsala, Sweden; Department of Breast cancer, Endocrine Tumors and Sarcoma, Karolinska University Hospital, Stockholm, Sweden; Department of Women’s and Children’s Health, Paediatric Oncology and Haematology, Childhood Cancer Research Unit, Karolinska Institute, Karolinska University Hospital, Astrid Lindgren Children’s Hospital, Stockholm, Sweden; Capio Palliative Care, Dalen Hospital, Stockholm, Sweden

ABSTRACT
The aim of this study was to explore the feasibility of the family talk intervention (FTI) and its acceptability to dependent children when a parent is cared for in palliative home care. The main goal of FTI is to increase family communication about the illness. The present paper derives from a pilot study and is based on 25 children’s reports, involving both questionnaires and interviews, after participation. A majority of the children appreciated the structure and content of FTI. They felt seen, heard, and acknowledged by the interventionists and recommended FTI to other children in similar situations.

Dependent children of parents with a life-threatening illness often express a need to communicate more within the family about their own feelings and issues related to their parent’s illness (Eklund et al., 2020a; Ellis et al., 2017; Morris et al., 2016). Appropriate illness-related information might reduce children’s feelings of guilt and fear, worries, and other psychological problems (Bugge et al., 2008; Dalton et al., 2019). Lack of information and weak communication within the family may cause long-term psychological distress for bereaved children (Bylund-Grenklo et al., 2014; Eilegård Wallin et al., 2016; Lövgren et al., 2018). In previous studies, parents expressed a need for support from professionals about how and when to talk to their children about illness and care (Dalton et al., 2019; Morris et al., 2016; Phillips, 2014).

When palliative care is provided in the home, children are confronted with both the parent’s illness, the care of it, and the imminent death. Specialized palliative home care is given by a multi-professional team, with specialist competence in palliative care, available 24 hours a day (Radbruch & Payne, 2009; Socialstyrelsen, 2013). In Sweden, health care professionals are, by law, responsible for acknowledging the needs of children living with a parent with a life-threatening illness and provide support and information to them (Government of Sweden, 2017). Since January 2020, the United Nations Convention on the Rights of Child (UNCRC) is regulated in Swedish law (Socialdepartementet, 2017) and children’s rights have thereby been strengthened; this applies also to children as relatives.

However, in palliative care, few evaluated psychosocial intervention studies including children are reported (Henoch et al., 2016; Kuhne et al., 2012). Evaluated interventions are mostly delivered to parents and children separately, aiming to increase knowledge about the illness and provide opportunities to meet others in similar situations. These interventions begin during palliative care and end during bereavement, using a psychotherapeutic approach focusing on grief or traumatology (Kuhne et al., 2012; Niemelä et al., 2010). Nevertheless, interventions involving the whole family, hereafter called family interventions, have been suggested to be effective in supporting all family members, mentally and physically (Wright & Leahey, 2013). Judging from previous studies in psychiatric care, such interventions are helpful for both dependent children and their parents in adapting self-understanding, developing a new perspective on the illness experience, and obtaining a shared understanding of the evolving situation (Beardslee et al., 1993, 1998; Focht & Beardslee, 1996; Pihkala et al., 2012a, 2012b).
A family intervention called the family talk intervention (FTI) has been developed and evaluated for psychiatric care, with promising results. The goal of FTI is to increase communication within the family about the illness, to support parenting, and build resilience (Beardslee et al., 1993). Furthermore, Beardslee (2002) states that the children should be in focus throughout FTI. To our knowledge, only two previous studies have evaluated FTI for families where a parent has a somatic illness (Bugge et al., 2008, 2009; Niemelä et al., 2012) and only one was from the children’s perspective (children aged 5–18 years). Participating children described that the intervention helped them feel more secure, increased their knowledge about the illness, and lessened feelings of sadness and other negative reactions (Bugge et al., 2008).

While FTI has shown promising results regarding family communication from both parents’ and children’s perspectives in other care contexts (Beardslee et al., 1993; Pihkala et al., 2012a, 2012b, 2017), it has not yet been evaluated in palliative care. The aim of this study was therefore to explore the feasibility of FTI in terms of acceptability from dependent children’s perspectives when a parent is cared for in palliative home care.

**Methods**

**Design**

This paper derives from a larger pilot intervention study that aimed to evaluate FTI in specialized palliative home care from the perspective of all family members (Eklund et al., 2018). This present paper focuses on the children’s experiences of feasibility in terms of acceptability. To provide insights and understanding of the children’s experiences, a convergent mixed-method design was used involving both questionnaires and interview data (Creswell & Plano Clark, 2018).

**Settings and participants**

Families were recruited for a 1-year period (March 2017 to February 2018) from two specialized palliative home care units providing 24-hour services from multi-professional teams, in Stockholm, Sweden. Inclusion criteria were that at least one parent had a life-threatening illness the families speak and write Swedish, and at least one child was aged 6–19 years. All children in the families were invited to participate. All 30 families that met the inclusion criteria were asked to participate in the study (Figure 1). Families were given written and verbal information about the study. Age-adapted information regarding the study was given to all children and written informed consent was obtained from parents/guardians of children under 15 years. Children over 15 years gave written informed consent for their own participation in accordance with Swedish law. In all, 20 families participated in the main study (Figure 1). The research received ethical approval from the Regional Ethical Review Board in Stockholm on 12 May 2016 (approval number 2016/664-31/5) and 20 February 2017 (approval number 2017/7-31/1).

**The family talk intervention**

FTI aims to increase communication within the family about the illness and to support parenting. Narrative and dialogical theories help family members share their stories and create a joint family history by seeing each other’s perspectives. Through this process, the family identifies its own strengths and resources to build on for the future. FTI also involves psychoeducation, and during the intervention, the family members increase their knowledge about the illness (Beardslee, 2002; Beardslee et al., 1998; Focht &
Beardslee, 1996). FTI is developed and designed for families with dependent children and has previously been used for families with children from the age of five years (Bugge et al., 2008).

FTI has six manual-based meetings with the whole family or part of it (Table 1), led by two interventionists (in this study: one deacon and one social worker), both of whom are educated and trained in the FTI method and have previous clinical experience of working with FTI in palliative care, as well as with families with dependent children in various care contexts. The researchers did not participate in intervention delivery. During the first two meetings, the parents share their stories. Meeting 3 involves the children and the interventionists, focusing on the children’s understanding of the illness and the situation, worries and questions. At meeting 4, the parents get feedback from meeting 3 and plan the family meeting (meeting 5), at which all family members are encouraged to talk about their own experiences. Meeting 6 focuses on how the family can move forward (Beardslee, 2002; Beardslee et al., 1993). FTI, in our study, followed the original manual; however, subjects that each family want to talk about may differ compared with when FTI is delivered in psychiatric care, as families in the context of palliative care face severe illness and imminent death, not psychiatric illness.

Of the 20 families included in this study, 14 families participated in all six meetings. In six families, some meetings were canceled due to deteriorating health or death (Table 2).

Data collection

After FTI was completed, a research group member contacted the families by phone to schedule an interview. Questionnaires were mailed to the families before the interview or handed over at the interview, whichever each family preferred.

Study-specific questionnaires

To evaluate FTI in this context, study-specific questionnaires were developed according to the method of Charlton (Charlton, 2000; Eklund et al., 2018). The questionnaires consisted of five parts: socio-demographics, illness-related information, family communication, psychosocial wellbeing, and experiences of FTI. Based on the feedback obtained throughout the process of validating the questionnaires, five questionnaire versions were developed: children 6–7 years; children 8–12 years; adolescents 13–19 years; healthy parent/other significant adults; ill parent. This was done because younger children managed fewer response options and questions than teenagers. The teenagers, therefore, received a more complex questionnaire, similar to that given to the adults.

For this study, data about the experiences of FTI were used. These questions were inspired by those in the study by Pihkala et al. (2010), who evaluated FTI in Swedish psychiatric care. Teenagers received nine closed-ended questions and younger children (aged 8–12 years) four closed-ended questions. Children aged 6–7 years did not get these questions. The questions covered if the intervention had encompassed

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**Table 1.** The family talk intervention: the focus of each meeting and the family members involved.

| Meeting | Family members involved | Focus of the meeting |
|---------|-------------------------|----------------------|
| 1       | Parents                 | The ill parent’s story. Parents’ concerns about the children. Setting up the family’s goals for the intervention. |
| 2       | Parents                 | The healthy parent’s/other significant adult’s story. How to prepare the children for meeting 3. |
| 3       | Each child (preferably without parents) | The child’s understanding of the illness and the situation, worries and questions. |
| 4       | Parents                 | Summarizing concerns and questions arising from meeting 3. Planning the family talk (meeting 5). |
| 5       | Parents and children    | “The family talk” preferably led by the parents and covering questions from both children and parents. |
| 6       | Parents and sometimes children | Follow-up with focus on how to communicate within the family in the future, to achieve the family’s goals. |

**Table 2.** Reasons for families canceling or altering meetings in FTI.

| Reason for canceling/altering meetings in FTI | Families (n = 20) |
|-----------------------------------------------|-------------------|
| Deteriorating health (meeting 4 was canceled) | 1                 |
| Family issues (no parent participated in meeting 5; meeting 4 was canceled; meeting 6 was canceled) | 3                 |
| Death of a parent (meetings 3 and 5 were canceled; meeting 4 was canceled) | 2                 |
enough meetings, the timing of the intervention, the experiences of talking with the interventionists without the parents, what it was like talking about thoughts and feelings during the meetings, and if the children would recommend the intervention. The children answered the questions on a three-point scale. One open-ended question was also included (if something regarding FTI could be done differently).

Interviews
The interviews focused on each family member’s experience of participation in FTI, communication within the family, and psychosocial wellbeing. They were held in the children’s homes and performed with one or two of the researchers. Three families were interviewed prior to their sixth meeting, while the others were interviewed between 5 days and 14 weeks after completion (mean 4 weeks). The wide timeframe was due to parental treatment or death. The researchers were flexible to each child’s and family’s wishes regarding if they wanted to be interviewed alone or with one or more family members. The researchers first initiated a family interview (Eggenberger & Nelms, 2007), for which the parents chose the location. To counterbalance any power asymmetries that might arise between adults (parents and researchers) and children, the researchers actively asked for children’s answers during the family interview. After these interviews, an interview was initiated with the child/children separately, for which the child/ren could choose the location. The vast majority of these interviews were performed in the child/ren’s own rooms, but some were performed in a kitchen or living room. The interviews were conducted with flexibility and sensitivity, by researchers with experience of working in palliative care and/or with children.

Twenty-two children participated in an interview (Figure 1); 12 were interviewed in the presence of one or more family members and ten were interviewed alone. The interviews lasted between 6 and 81 minutes depending on whether all or part of the family participated, or only the child. Interviews were tape-recorded and transcribed verbatim.

Data analysis
Data were analyzed using the procedures of a mixed-method convergent design, as explained by Creswell and Plano Clark (2018). Descriptive statistics (frequencies) were used to analyze the answers from the closed-ended questions, using IBM SPSS Statistics version 24. A conventional content analysis was used to analyze the open-ended question (if FTI could have been done differently) and the interviews (Hsieh & Shannon, 2005).

All authors read the interview transcripts to get a sense of the whole. Thereafter, meaning units from the transcripts were selected and sorted into codes through comparisons of similarities and differences (first and second author); this resulted in 10 codes. Next, categories were constructed by the first, second, and last author based on similarities in content, which resulted in two categories, with one category including two subcategories (Table 3). All steps were discussed by all authors until consensus was reached. Next, the results from the quantitative and qualitative analyses were merged in accordance with the mixed-method convergent design (Creswell & Plano Clark, 2018); the authors searched for common concepts across the results by comparing and sorting them. After that, the authors determined in what way the results from the quantitative and qualitative analyses confirmed, disconfirmed, or expanded each other.

Results
Children’s characteristics
A total of 25 children participated, aged 8–17 years (8–12 years, \( n = 13 \); 13–17 years, \( n = 12 \)). Ten of the children lived in nuclear families, 13 in step-families, and two had a single parent. All but four had siblings. Of the 16 ill parents, 13 had cancer. We used the term younger children for children aged 8–12 years and the term teenagers for children aged 13–19 years. We use the term children to refers to both age groups.

Children’s experiences of the family talk intervention
The results from questionnaires and interviews are described below. The headings are the categories and sub-categories that emerged in the analysis process: Category 1: The structure and content of FTI; Sub-category 1: FTI was appreciated overall; Sub-category 2: Being seen, heard and acknowledged during FTI. Category 2: Recommending FTI to other children (Tables 3 and 4). For readability, the questionnaire results are presented first, followed by the interview results.
Table 3. Joint display of mixed-method convergent analysis in accordance with Creswell and Plano Clark (2018).

| Quantitative results | Qualitative results | Mixed method comparison | Categories and sub-categories |
|----------------------|---------------------|--------------------------|-----------------------------|
| Frequencies          | Codes & exemplar quotes | Confirmation | The structure and content of FTI: FTI was appreciated overall. |
| Timing               |                     | FTI came at the right time for participating teenagers. |                          |
| 13–19 years: 91% yes |                     | Confirmation | A majority of the children reported that FTI included a sufficient number of meetings. |
|                      | Timing              | Expansion       | Recognition of the need for additional meetings varied between family members. |
|                      |                     | Discordance    | While all teenagers said FTI met their expectations in the questionnaires, some mentioned during the interviews that participation in FTI was difficult. |
| Sufficient numbers of meetings |                     | Confirmation | Children felt listened to. |
| 8–12 years: 92% the right number | Number of meetings | Expansion       | Children felt that the interventionists truly cared about them. |
| 13–19 years: 53% the right number | A sufficient number of meetings | Discordance | The children trusted the interventionists, as the interventionists asked what they could tell their parents and what should remain a secret. This created trust and security. |
| Met expectations     |                     | Understanding   | The structure and content of FTI: FTI was appreciated overall. |
| 13–19 years: 100% yes or partially (1 missing) | The experience of the design of FTI | Confirmation | FTI came at the right time for participating teenagers. |
|                      | Yeah, you get a good structure if they take part… they take charge a bit (16 years) | Expansion       | Recognition of the need for additional meetings varied between family members. |
|                      | The interventionists’ competence | Discordance    | While all teenagers said FTI met their expectations in the questionnaires, some mentioned during the interviews that participation in FTI was difficult. |
|                      | You can tell that they are good at this and have been doing it for a while (16 years) | Confirmation | Children felt listened to. |
|                      | The contents of the meetings | Expansion       | Children felt that the interventionists truly cared about them. |
|                      | … talked a bit asked how I was doing how the family was doing at home and what my experiences were from… because everyone has very different perspectives… how you perceive situations… so she asked a bit about how I’d experienced it yeah, about who I could talk to… what I was feeling (17 years) | Discordance | The children trusted the interventionists, as the interventionists asked what they could tell their parents and what should remain a secret. This created trust and security. |
|                      | Feeling it was a bit too much | Confirmation | FTI came at the right time for participating teenagers. |
|                      | That was when (talking about the family meeting) I felt that I found out a bit too much that I didn’t want to because I actually said that I didn’t want to interfere or get involved but yeah so I said that then I just stayed out of it (14 years) | Expansion       | Recognition of the need for additional meetings varied between family members. |
|                      | All the meetings have been a bit difficult (17 years) | Discordance    | While all teenagers said FTI met their expectations in the questionnaires, some mentioned during the interviews that participation in FTI was difficult. |
| Understood by the interventionists | That the interventionists listened and cared | Confirmation | Children felt listened to. |
| 8–12 years: 100% yes or partially (1 missing) | Yeah, I think that… no, but that… NN and NN (the interventionists’ names) listened uhm more… so… yeah, but it felt like they really cared than just like going through questions so that like helped yeah… (13 years) | Expansion       | Children felt that the interventionists truly cared about them. |
| 13–19 years: 100% yes (1 missing) | All the meetings have been a bit difficult (17 years) | Discordance    | While all teenagers said FTI met their expectations in the questionnaires, some mentioned during the interviews that participation in FTI was difficult. |
| Easy to talk to the interventionists | Feeling security and trust during the meeting | Confirmation | FTI came at the right time for participating teenagers. |
| without parent’s     | They said that some parts they might talk about… but uhm… uhm they also asked later if they could mentioned this like yeah, can I talk about this later, like… so that… that wasn’t a problem… so I could talk about anything I wanted to (16 years) | Expansion       | Recognition of the need for additional meetings varied between family members. |
| 8–12 years: 83% yes (other: neither easy nor difficult) | Feeling security and trust during the meeting | Confirmation | FTI came at the right time for participating teenagers. |
| 13–19 years: 64% (9% difficult, 27% neither easy nor difficult) | They said that some parts they might talk about… but uhm… uhm they also asked later if they could mentioned this like yeah, can I talk about this later, like… so that… that wasn’t a problem… so I could talk about anything I wanted to (16 years) | Expansion       | Recognition of the need for additional meetings varied between family members. |

(Continued)
The structure and content of FTI

FTI was appreciated overall

All but one teenager reported that FTI came at the right time. The same number of teenagers also reported that FTI met, or partially met their expectations. A majority (17/23) of all children reported that FTI included a sufficient number of meetings. However, 5/23 reported that there were too few meetings (Table 4). One teenager acknowledged that the need for additional meetings varied between family members:

I personally probably wouldn’t have needed to talk to them more but I know that the others would have wanted to talk to them more and because you know I don’t like to talk about so then this is kind of enough for me (13 years)

Some children described it as having gone by too fast for them to get to share everything: “Uhm, like, yeah, it went by awfully fast, but yeah it was awfully few times” (11 years). On the other hand, the children stated that it was good that someone outside the family led the meetings and that FTI facilitated communication within the family during these meetings: “So that just makes it better because you become more open and maybe it doesn’t always feel really natural you know when you don’t have any questions or like yeah” (13 years). The children perceived the interventionists as competent; they reported that they noticed that the interventionists had a lot of experience doing this and that they asked good and relevant questions.

They stated that the meetings primarily included conversations about the parent’s illness (regarding both their understanding of it and a lack of information), how they felt, and who they could talk to outside of the family. One younger boy said that he appreciated that the interventionists gave him information regarding his parent’s illness:

It was good talking to her (talking about one of the interventionists) and uhm and a lot of information uhm, yeah uhm more about Dad’s illness and if and yeah if you could cure it and uhm that (The interviewer asks: Can you cure it?) Mmm, no but you make it so that you uhm that he lasts longer (10 years)

However, not all children were entirely satisfied with FTI; some had experienced both satisfaction and some difficulties regarding their participation. One teenager said:

That was when (talking about the family meeting) I felt that I found out a bit too much that I didn’t want to because I actually said that I didn’t want to interfere or get involved but yeah so I said that then I just stayed out of it (14 years).
Another teenager reported that FTI was both good and difficult at once. First, she asked for more meetings, for all family members: “But I think maybe we should have had more meetings than just these and over a longer period because it was like quite short because Dad will be ill for a long time and we will need help” (17 years), and after that, she said “All the meetings have been a bit difficult” (17 years). In the open-ended question in the questionnaire, two children suggested improvements. One wrote, “For example, approaching the topic more slowly. Instead you can say like how was school today, that you take it step by step” (11 years). The other wrote, “The message maybe … You presented it as if it would help us talk but that part hasn’t really changed. But it was nice talking” (15 years). During an interview, another younger child said, “Sometimes there were a bit too many questions” (11 years).

**Being seen, heard, and acknowledged during FTI**

Twenty of the twenty-three children reported that they felt that the interventionists understood them (none reported that they did not feel understood) and that it was easy to talk to them, even if their parents were not there (17/23). All but one teenager reported that they could talk entirely or partially openly with the interventionists about their thoughts and feelings (Table 4). One younger child stressed the importance of FTI not being focused only on the situation: “The things I liked about the support program were that they did not just talk about what it was like in the situation, but also about me and what I do outside school and so on” (11 years). Children reported that they felt listened to and felt that the interventionists really cared about them.

That approach was appreciated by the children, as one teenager reported: “Yeah, I think that no, but that NN and NN (the interventionists’ names) listened umh more so yeah, but it felt like they really cared than just like going through questions so that like helped yeah” (13 years). The children stated that they trusted the interventionists, that the interventionists had made a positive impression on them, and that it was easy to show them their feelings. They also reported that when the interventionists asked what they could tell their parents and what should remain a

| What did you think of the number of meetings included in the support program? | Children, 8–12 years (n = 12) | Teenagers, 13–19 years (n = 11) |
|---|---|---|
| The right number: 11 | The right number: 6 |
| Too few: 1 | Too few: 4 |
| Too many: 0 | Too many: 0 |
| Missing: 0 | Missing: 1 |

| Did you feel understood by the people leading the support program? | Children, 8–12 years (n = 12) | Teenagers, 13–19 years (n = 11) |
|---|---|---|
| I felt that they understood me: 10 | I felt that they understood me: 10 |
| I felt that they partially understood me: 2 | I felt that they partially understood me: 0 |
| I felt that they did not understand me: 0 | I felt that they did not understand me: 0 |
| Missing: 1 | Missing: 1 |

| What was it like talking to the people leading the support program when your parents weren’t there? | Children, 8–12 years (n = 12) | Teenagers, 13–19 years (n = 11) |
|---|---|---|
| Easy: 10 | Easy: 7 |
| Neither easy nor difficult: 2 | Neither easy nor difficult: 3 |
| Difficult: 0 | Difficult: 1 |
| Missing: 0 | Missing: 0 |

| Did you think it was good getting to talk to the people leading the support program without having your parents there? | Children, 8–12 years (n = 12) | Teenagers, 13–19 years (n = 11) |
|---|---|---|
| Yes: 9 | Yes: 8 |
| No: 0 | No: 0 |
| I don’t know: 3 | I don’t know: 3 |
| Missing: 0 | Missing: 0 |

| Could you talk openly about your thoughts in the meetings within the support program? | Children, 8–12 years (n = 12) | Teenagers, 13–19 years (n = 11) |
|---|---|---|
| Yes, entirely: 7 | Yes, entirely: 7 |
| Yes, partially: 3 | Yes, partially: 5 |
| No: 0 | No: 0 |
| Missing: 1 | Missing: 1 |

| Could you talk openly about your feelings in the meetings within the support program? | Children, 8–12 years (n = 12) | Teenagers, 13–19 years (n = 11) |
|---|---|---|
| Yes, entirely: 5 | Yes, entirely: 5 |
| Yes, partially: 5 | Yes, partially: 5 |
| No: 0 | No: 0 |
| Missing: 1 | Missing: 1 |

| Do you feel that the support program came at the right time for you and your family? | Children, 8–12 years (n = 12) | Teenagers, 13–19 years (n = 11) |
|---|---|---|
| Yes: 10 | Yes: 10 |
| No, it came too early: 0 | No, it came too early: 0 |
| No, it came too late: 1 | No, it came too late: 1 |
| Missing: 0 | Missing: 0 |

| Has the support program met your expectations? | Children, 8–12 years (n = 12) | Teenagers, 13–19 years (n = 11) |
|---|---|---|
| Yes, entirely: 5 | Yes, entirely: 5 |
| Yes, partially: 5 | Yes, partially: 5 |
| No: 0 | No: 0 |
| Missing: 1 | Missing: 1 |

| Would you recommend the support program to other families in similar situations? | Children, 8–12 years (n = 12) | Teenagers, 13–19 years (n = 11) |
|---|---|---|
| Yes: 10 | Yes: 10 |
| No: 0 | No: 0 |
| Missing: 1 | Missing: 1 |
secret, this created trust and security. Many children said it was a relief having talked to the interventionists. Some said that the immediate relief after the meeting was linked to having an opportunity to speak to someone about their own life situation:

It feels like you’re weighed down by all of this and as soon as you just get like you don’t need to get advice or anything, just that you can like talk about it say it, then it feels like you’ve like that it’s easier that you’ve let it all out (13 years)

One teenager talked about how significant it had been when the interventionists, during the child meeting, had told him positive things about himself, and thus improved his self-confidence and self-esteem:

Yeah, I was there by myself talking to NN and NN (the interventionists’ names) and then we talked about Mom’s illness of course uhm it went well, I didn’t cry and I was doing well, I didn’t feel anything like I wasn’t sad while we were talking or anything, it went well and then I left there it’s like those things that they say, they can say good things about you like you are strong or that means a lot actually uhm that someone says that to you uhm so you left with a bit more self-esteem anyway. (14 years)

**Recommending FTI to other children**

All teenagers recommended FTI to other children in similar situations (one missing; Table 4) and nine children talked about this during the interviews. They clarified that it was good being able to speak to someone about their thoughts:

Because like you can talk about what you’re thinking and, and not like because otherwise it might be that you walk around thinking about it a lot and you can like, you can like, like, I don’t know how to explain it, but (silence) you know so that you don’t put aside, that you deal with it (11 years)

**Discussion**

The results of this study showed that the vast majority of the children appreciated the structure and content of FTI. The children, with some exceptions, reported that there were enough meetings, and all but one teenager reported that FTI came at the right time. They said it was good that someone outside the family supported them in talking to each other. The children felt seen, heard, and acknowledged by the interventionists during FTI, which established trust and security. They also reported that it was an immediate relief getting the possibility to talk about feelings related to the situation, although a few said that it had also been difficult. FTI was recommended to other children in similar situations.

A key recommendation in assessing the feasibility of a complex intervention from the recipients’ perspective relates to the concepts of acceptability and delivery (Campbell et al., 2000; Craig et al., 2008; Hagen et al., 2011). Both intervention delivery and participation in research are challenging in the palliative care context, due to a range of different factors, such as physical symptoms and death. However, previous research shows that families in palliative care want to participate in research, and report their participation as a positive experience. Therefore, it is important to—and even unethical not to—explore how families in palliative care, regardless of illness and symptoms, experience their participation in both interventions and research, and how the feasibility of interventions is experienced (Chambers et al., 2019; Higginson et al., 2013). This study reported that the number of meetings was reasonable, which suggests rather good acceptability from the children’s perspective. However, five children reported that there were too few meetings and that they did not have time to share everything. On the other hand, the teenagers reported that the intervention had met their expectations partially or entirely and they would recommend FTI to other families in similar situations. This would suggest the acceptability of FTI in specialized palliative home care for the children participating in this study. Moreover, the teenagers reported that the timing of FTI was satisfactory, which suggests that the delivery of the intervention was feasible (Campbell et al., 2000; Craig et al., 2008). These findings are mostly in line with the parents’ experiences of FTI (Alvariza et al., 2020), strengthening the overall acceptability of FTI in palliative home care.

However, some children mentioned difficulties regarding participation in the family meeting (Meeting 5). These findings can be viewed in the light of findings from earlier studies regarding the children’s experiences of FTI in palliative home care (Eklund et al., 2020b; Eklund, Alvariza, et al., 2020).

Most of the children, regardless of age, reported that participating in FTI was a positive experience overall with a few exceptions, which is in line with children’s reports in other studies and contexts (Bugge et al., 2008; Pihkala et al., 2012a, 2012b; Solantaus et al., 2009). Meeting 3, the child meeting has been described as both easy to participate in and somewhat scary, as it means talking to the interventionists alone (Bugge et al., 2008; Solantaus et al., 2009). None of the children in this study reported that meeting 3 was
negative. Rather, they felt seen, heard, and acknowledged, which is in line with previous research on FTI in other contexts (Bugge et al., 2008; Pihkala et al., 2012a, 2012b; Solantaus et al., 2009).

In contrast to our results, where all but one teenager reported that they felt that the interventionists understood them, another study in the psychiatric care context found that younger children more often than teenagers felt that the interventionists understood them (Pihkala et al., 2010). The family meeting has sometimes been reported as difficult for children (Solantaus et al., 2009), which some children in this study confirmed. Some children wished that the interventionists had been more sensitive in bringing up certain topics (e.g., the parent’s illness and imminent death). A difference between FTI in the palliative care context and in the psychiatric care context is the imminent death that families in palliative care are facing. Most children want to know and talk about illness and death (Alvariza et al., 2017; Eklund et al., 2020a; Bluebond-Langner et al., 2012). A previous study showed that FTI had a potentially positive effect on talking about, and preparing for, the dying process, the imminent death, and what would happen afterward (Eklund et al., 2020). However, it is important that the interventionists are receptive to the children’s individual needs. FTI is developed to suit families with children in a wide age range and children are not a homogenous group. It is therefore important that those who deliver FTI not only take the children’s age into account, based on a developmental perspective—for example, when giving information in order to increase knowledge about the illness or talking about imminent death—but also see the children’s competence and comprehension of death in a wider perspective. This includes the family’s social, cultural, and economic circumstances and the children’s previous experiences and education level; each child’s own competence needs to be taken into account when working with them (Coyne & Harder, 2011; Bluebond-Langner et al., 2012).

Taken together, these findings indicate that when FTI is set up for a full-scale trial in palliative care, a child-centered focus should be included in the intervention delivery, in parallel with the family-centered focus that FTI has in its original form. The reason for this is that FTI has a structure that mainly benefits the parents, as they get more meetings with the interventionists, as well as participating in the first meetings, which set the agenda and the goals for the family’s participation. As a suggestion, the FTI education program could include a section on child-centered care. This would serve to ensure that the children’s voices are heard during their participation in FTI, which might reduce the difficulties related to the children’s participation in the family meeting (Meeting 5). The inclusion of a child-centered focus is also in line with the fact that the UNCRC has become law in Sweden, as the convention states that adults must ensure that children’s perspectives are taken into account.

As far as we know, this study is the first that evaluates FTI in palliative care. Moreover, it is the first FTI study that explores children’s perspectives using mixed methods, which is preferred when evaluating a complex intervention (Farquhar et al., 2011). In this study, no parental proxies were used, due to the importance of exploring the children’s own experiences. When children participate in research, it is important to create a feeling of safety, so the children dare respond honestly (Eder & Fingerson, 2001). We have therefore been flexible to the children’s wishes regarding how questionnaires were designed and how interviews were conducted (Eklund et al., 2018). This flexibility is a strength in the study, as almost every child who participated in FTI also wanted to participate in an interview with the researchers, with or without a family member present. It can be easier for the children to talk to researchers when some or all family members participate together, as it gives an increased feeling of security. At the same time, this could also be a limitation to the study, as there might be an imbalance of power between adults and children. Furthermore, parental interactions and interruptions might affect the children’s narratives, as parents, explicitly or implicitly, define what is relevant to relate (Mason & Tipper, 2014). There is also a risk that the content may differ between interviews when mixing interview procedures in this manner.

In summary, the children saw FTI as a positive experience overall, regarding content, structure, timing, and interactions with the interventionists. This study focuses on the children’s experiences of FTI and we intend to report results from all family members’ perspectives regarding feasibility and outcome. As this study involves a small sample of Swedish-speaking families in a large city, it may limit the transferability of our findings outside the Swedish context, or to other children with a parent cared for in palliative care. Rather, this study indicates the direction of a future full-scale trial in palliative care, as it seemed feasible from the included children’s perspective.
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ORCID

Rakel Eklund http://orcid.org/0000-0002-9396-9800
Li Jalmsell http://orcid.org/0000-0001-5524-0843
Ulrika Kreicbergs http://orcid.org/0000-0002-8185-781X
Anette Alvariza http://orcid.org/0000-0003-2711-0245
Malin Lövgren http://orcid.org/0000-0003-4736-500X

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