

## Original Article

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# Breaking the silence about illness and death: Potential effects of a pilot study of the family talk intervention when a parent with dependent children receives specialized palliative home care

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## Abstract

**Objective.** The entire family is affected when a parent is severely ill. Parents often need and appreciate professional support when talking to children about illness and death. The family talk intervention (FTI) is family-centered and intends to promote communication about the illness and its consequences, support parenting to enhance family coping and help family members share experiences with each other to create a shared family history. This study aimed to explore potential effects of FTI in specialized palliative home care, as reported by parents.

**Method.** This pre-post test intervention pilot was conducted in specialized palliative home care. A convergent mixed-method design was used to analyze interview and questionnaire data. Twenty families with dependent children were recruited from two specialized palliative home care units in Stockholm, Sweden.

**Results.** Parents reported that family communication improved after participation in FTI as family members learned communication strategies that facilitated open sharing of thoughts and feelings. Increased open communication helped family members gain a better understanding of each other's perspectives. Parents reported that relationships with their partner and children had improved as they now shared several strategies for maintaining family relationships. Parents were also less worried following participation in FTI. The ill parents stated that they gained a sense of security and were less worried about the future.

**Significance of results.** This study adds to the evidence that FTI may be a useful intervention for families with dependent children and an ill parent in a palliative care setting. This trial is registered at ClinicalTrials.gov Identifier NCT03119545.

## Introduction

Parents facing life-threatening illness experience extreme stress while struggling to cope with their illness and treatment, uphold family routines and maintain parenting roles (Semple and McCance, 2010; Dalton et al., 2019). Co-parents strive to assume the roles of both parents, while simultaneously managing their partner's care and balancing their own needs with the needs of their partner and children (Aamotsmo and Bugge, 2014; Park et al., 2017; Hanna et al., 2019).

Common concerns of ill parents include the welfare of their children, how to meet their children's emotional needs, and how to communicate about their illness (Semple and McCance, 2010). Several studies have shown that parents needed and appreciated professional support when talking to children about illness and death (Shands et al., 2000; Helseth and Ulfset, 2005; Stiffler et al., 2008; Semple and McCance, 2010; Aamotsmo and Bugge, 2014; Dalton et al., 2019). Research has unfortunately shown that families seldom receive this type of support (Semple and McCance, 2010; Dalton et al., 2019; Hanna et al., 2019) which may lead to poorer adjustment for families, whereas open communication may lead to increased satisfaction in parents and have positive effects on children's psychological health (Huizinga et al., 2005; Houck et al., 2007; Dalton et al., 2019; Hanna et al., 2019; Weber et al., 2019). Furthermore, family health can be maintained and supported if interventions encompass each individual family member, as well as the family unit as a whole (Wright and Leahey, 2013). Family-centered interventions focusing on the family as a whole (Coyne et al., 2018) often improve family members' understanding of their own and each other's perspectives and the parent's illness (Beardslee et al., 1993; Focht and Beardslee, 1996; Beardslee et al., 1998; Pihkala, 2012; Wright and Leahey, 2013; Eklund et al., 2020a).

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The family talk intervention (FTI) is family-centered and was originally developed to support families where a parent of dependent children has an affective disorder (Beardslee *et al.*, 1997, 2003; Beardslee, 2002). The goal of FTI is to promote family communication about the illness and its consequences and to support parenting to enhance family coping. Furthermore, FTI helps family members share their experiences with each other to create a shared family history using an eclectic approach including psycho-educative, narrative, and dialogical approaches. The psycho-educative element increases knowledge about the illness and related subjects for all family members. The interventionists may invite the ill parent's doctor to a meeting to ensure that all family members have an opportunity to have their questions answered. The narrative element involves the family's own stories. The dialogical way of working helps to make problematic situations visible by sharing experiences within the family and considering each family members' differing perspective (Focht and Beardslee, 1996; Beardslee *et al.*, 1998, 2003). FTI is based on six key concepts: Sharing a history together, Bringing knowledge about the illness, Addressing the needs of the children, Planning how to talk to the children, Breaking the silence together as a family, and Continuing the family dialogue, moving on and facing the future (Focht and Beardslee, 1996; Beardslee *et al.*, 1998, 2003).

Providing opportunities for open, honest communication with patients and their families is meant to be current practice in palliative care. However, healthcare professionals report that they find supporting the family challenging when children are involved (Franklin *et al.*, 2019). There are also few manual-based family interventions scientifically evaluated in this context (Ellis *et al.*, 2017). FTI may offer a structured approach for communicating with patients and families ensuring that all families receive the same quality of support.

In a study of a modified version of FTI when a parent has incurable cancer, parents reported gaining greater insight into their children's thoughts and reaction as well as how the family situation was affecting their children's daily lives. They also reported reduced family conflict and that they talked more openly about the family situation (Bugge *et al.*, 2009). In the same study, children reported that participating in the modified version of FTI helped them to feel more secure, increased their knowledge and understanding of the family's situation and who they could turn to for support and helped them to realize that it was helpful to talk about the family situation (Bugge *et al.*, 2008).

Previously, we reported that FTI was feasible in terms of acceptability, in specialized palliative home care, from the perspective of parents (Alvariza *et al.*, 2020). We have previously reported the results for the children who participated in this study with focus on feasibility (Eklund *et al.*, 2020b) and also found that FTI was effective at providing participating children with illness-related information, improving family communication, helping children prepare for the future, reducing family conflicts, and helping children to build resilience (Eklund *et al.*, 2020c). However, it is not known how the parents in the participating families were affected. The current study, therefore, aims to explore potential effects of FTI in specialized palliative home care from the ill parent's and co-parent's perspectives.

## Methods

### Design

This is a pre-post test intervention pilot conducted in specialized palliative home care (Eklund *et al.*, 2018). Questionnaires were

completed at baseline (March 2017–March 2018), upon completion of FTI, and 1 year post-baseline. Interview data were collected upon completion of FTI. In order to better understand the potential effects of FTI as reported by the parents, a convergent mixed-method design was used (Creswell and Plano Clark, 2018). The study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2014) and ethical approval was obtained from the Regional Ethical Review Board in Stockholm (2016/664-31/5 and 2017/7-31/1).

### The family talk intervention

FTI is manual-based and entails six meetings with FTI-educated interventionists (in this study, one social worker and one deacon both of whom had worked with the intervention for several years prior to this study) (Table 1), with intervals of 1–2 weeks between the meetings. Each meeting is 1–2 h long. Meetings one, two, and four include the parents and interventionists. Meeting three involves the child(ren) and interventionists, and meetings five and six include the whole family. In meetings one and two, the parents each share their own story of the illness with the interventionists and set the goal with the intervention for the family. In meeting three, the child shares their understanding of their parent's illness with the interventionists, and the interventionists focus on the children's risk and resilience factors. Meeting four is used to summarize the main topics discussed in meetings one, two, and three and plan for "The Family Talk" which takes place in meeting five. Meeting six is a follow-up meeting with the family. The meetings are held in a place chosen by the family, often in their home. The researchers were not involved in delivering the intervention.

### Participants and procedure

Families were recruited from two specialized palliative home care services in Stockholm, Sweden. The services were staffed by multi-professional teams, including physicians, social workers, physical and occupational therapists, nutritionists, and nurses. They provide 24-h support to patients with advanced incurable illness who have complex palliative care needs, regardless of diagnosis, in their own homes. Patients receive assistance with advanced symptom relief, and personal care as well as emotional and existential support.

Inclusion criteria were (1) at least one parent with a life-threatening illness, (2) at least one child aged 6–19 years, and (3) ability to speak and write Swedish. In accordance with patient privacy laws, the research group received the patient's contact information. Each participating family then decided which family members would participate. Eligible families were invited to participate and received written and verbal information about the study. Age-adapted information was given to children under 15 years. Twenty families out of an eligible 30 (participation rate 67%) consented to participate in FTI (Table 2).

### Data collection and measurements

Data were collected at baseline (questionnaire), upon intervention completion (questionnaire, interviews) and one year after baseline (questionnaire). Upon completion of FTI, 12 ill parents and 17 co-parents participated in a follow-up interview. In total, 20 ill parents (11 male, 9 female) with a mean age of 48 years

**Table 1.** The family talk intervention: contents of each meeting and participants included

Meeting	Participants	Contents
1	Parents and two interventionists	The ill parent shares their story. Parents share concerns regarding the children. Family goals for the intervention are set.
2	Parents and two interventionists	The co-parent shares their story. Discussion on how to prepare the children for Meeting three.
3	Each child individually or with siblings (preferably without parents) and two interventionists	The child shares their understanding of the parent's illness and the family's situation and raises any questions or concerns.
4	Parents and two interventionists	Summarization of questions and concerns which arose during Meeting three. Planning "the family talk" (Meeting five).
5	Parents and children and two interventionists	"The family talk," parents lead a discussion (with support from the interventionists when needed) which covers children's and parents' questions and concerns.
6	Parents (sometimes children) and two interventionists	Follow-up meeting focusing on how to communicate as a family in the future in order to achieve the family's goals.

**Table 2.** Participants

Family number	Family constellation	Illness
1	Ill father, <sup>1</sup> mother, child 16 years, child 13 years	Cancer
2	Ill father, <sup>2</sup> mother, child 12 years, child 10 years	Cancer
3	Ill mother, child 17 years, child 13 years	Cancer
4	Ill mother, <sup>1</sup> father, child 24 years, child 22 years, child 20 years, child 13 years, child 10 years	Cancer
5	Ill mother, father, child 13 years, child 12 years, child 8 years	Other <sup>a</sup>
6	Ill mother, father, child 16 years, child 11 years, child 10 years, child 7 years	Other <sup>a</sup>
7	Ill mother, father, child 17 years	Cancer
8	Ill father, <sup>2</sup> mother, child 13 years, child 12 years, child 8 years	Cancer
9	Ill mother, <sup>1</sup> father, child 12 years	Other <sup>a</sup>
10	Ill father, mother, child 25 years, child 22 years, child 12 years	Cancer
11	Ill mother, father (did not participate in FTI), child 13 years and a baby	Cancer
12	Ill father, <sup>3</sup> mother, child 10 years, child 8 years, child 4 years	Cancer
13	Ill mother, father, child 17 years, child 10 years	Cancer
14	Ill father, <sup>2</sup> mother (ex-wife 1), mother (ex-wife 2), child 10 years, child 4 years	Cancer
15	Ill mother, father, child 22 years, child 20 years, child 12 years, child 11 years	Cancer
16	Ill father, <sup>3</sup> mother, child 16 years, child 5 years, child 5 years	Cancer
17	Ill father, mother, child 15 years	Cancer
18	Ill father, mother, child 22 years, child 20 years, child 17 years, child 16 years, child 13 years	Cancer
19	Ill mother, child 32 years, child 14 years	Cancer
20	Ill father, mother, child 8 years	Cancer

<sup>1</sup>Died before follow-up 1.

<sup>2</sup>Died before follow-up 2.

<sup>3</sup>Died during family's participation in the family talk intervention (FTI).

<sup>a</sup>Advanced pulmonary disease, gastric bleeding due to Dieulafoy's lesion, chronic liver disease.

participated, as did 19 co-parents (7 male, 12 female) with a mean age of 44 years.

Study-specific questionnaires were developed (Charlton, 2000; Eklund et al., 2018) with separate versions for the ill parent and the co-parent. The questionnaires consisted of single-item questions regarding socio-demographics, illness-related information, family communication, psychosocial well-being, and experiences of participating in FTI. Questions were scored using a four-point Likert scale with response alternatives "do not agree at all,"

"somewhat agree," "agree for the most part," and "completely agree." See Table 3 for a list of questions included in this study.

Interviews were used to capture participants' unique experiences using their own words. All families were invited to participate in an interview after participating in FTI. The researchers were flexible to families wishes regarding constellations, and time and place for the interview. All but one of the interviews were held in family homes and were conducted by one or two of the researchers. The interviewers strived for openness in

**Table 3.** Questions asked at baseline and follow-up

Questions answered by the ill parent and co-parent
I can talk about the illness with someone in my family.
I am satisfied with the conversations my family have about the illness.
I can talk about how I feel with someone in my family.
I have thoughts that I do not want to share with anyone in my family.
I am satisfied with the time I spend together with my family.
I would like to talk more about the illness with someone in my family.
I am worried about someone in my family.
I want to talk more with my family.

eliciting each participant's experience, and the interviews focused on illness-related information, family communication, psychosocial well-being, and their experiences of the structure and content of FTI. The interviews lasted between 17 and 81 min (depending on the number of participants and their health status) were audio-recorded and transcribed verbatim. Reasons for not participating were related to declining health or death.

### Analysis

Wilcoxon signed-rank tests were conducted for paired comparisons of ill parent and co-parent reports on the single-item questions from the baseline and follow-up questionnaires. Analyses were conducted comparing data from baseline and follow-up one and data from baseline and follow-up two.

Inductive qualitative content analysis was applied to the interviews (Elo and Kyngäs, 2008). Open coding was conducted by the first and last author while each interview was read several times. Codes were recorded on a coding sheet and grouped into subcategories which were collapsed into broader categories. Abstraction was used throughout the analysis process. Categories were adjusted until all the authors agreed that they were clear and concise enough to describe the effects of FTI.

Quantitative and qualitative results were merged using the procedures of a mixed-method convergent design as described by Creswell and Plano Clark (2018). The authors searched for common concepts in the qualitative and quantitative results by comparing and sorting them into domains, after which they determined how the qualitative and quantitative results confirmed, disconfirmed, or expanded upon each other.

### Results

The results are presented below under the four categories which emerged from the qualitative analysis. Quantitative results related to each category are presented below, together with the qualitative results for each respective category.

#### Talking together as a family

No statistically significant results were found regarding the questions "I can talk about how I feel with someone in my family," "I have thoughts I don't want to share with anyone in my family," or "I want to talk more with my family". However, in contrast to the quantitative results, many parents stated during the interviews that family communication had improved in several ways since

participating in FTI. Based on the interviews, family communication improved as parents gained a new understanding of each other's perspectives. The wife of an ill father stated: "I think it has given us a lot, it has especially helped us gain a better understanding of each other's differences in a new way." Parents also stated that it felt more natural to have deeper conversations than it had before FTI.

Parents stated that they and their children had the opportunity to voice concerns and show their positive and negative characteristics while participating in FTI. While many parents considered the sessions to be difficult and described feelings of dread or worry before each session, they also mentioned how talking openly during the sessions led to feelings of relief and calm afterward. An ill father said: "But it hit us that everyone thought it was really difficult and uncomfortable to engage in those conversations but it felt better after the conversation was over."

Furthermore, parents explained that they were grateful for the opportunity to talk together as a family in a dialogue led by the interventionists. They felt this encouraged vulnerability and allowed participating family members to raise difficult topics and sort out emotional issues, which they may previously have been avoiding due to discomfort or not wanting to upset others. An ill father said:

I think it has been good that we have been able to sit down so to speak, and talk about these things, otherwise I don't think it would have happened, between [my partner] and me ... and I think it helped the children too, to come into this situation.

#### Sharing illness-related information

At the first follow-up, the ill parents wanted to talk more about their illness with someone in their family ( $z = -1.89$ ,  $p = 0.05$ ). The ill parents' satisfaction with the family conversations regarding their illness increased between baseline and the second follow-up ( $z = -2.23$ ,  $p = 0.02$ ). There were no significant results regarding the question "I can talk about the illness with someone in my family." The ill parents did not directly address these questions during the interview. Instead, they stated that they learned to speak openly and honestly about the symptoms, side effects of treatment and prognosis, hoping to alleviate family members' anxiety, worry, and uncertainty. Both the ill and especially the co-parents seemed to be more focused on how the family as a whole had increased their knowledge and understanding of the parent's illness through FTI, indicating that they had talked more about the illness. A father, whose wife was ill, said: "So then we gathered all the children because the doctor was finally going to talk to us about what was happening. It was like a little conference where everyone could talk about what was happening." This meeting with the doctor was arranged in response to the advice from, and with the help of, the FTI interventionists.

Despite the lack of statistically significant quantitative results for co-parents regarding these questions, the co-parents did report during the interviews that they were striving to speak more about their partner's illness. This may indicate that the co-parents did not want to talk more about the illness, as indicated by the quantitative results, but that they tried to speak more about it anyways for the sake of their partner and children. The ex-wife of an ill father explains: "I think I have tried to be as direct and honest as possible, you don't need to get into the smallest details, but all of the information I have received, [our child] has also received."

### Maintaining family relationships

No statistically significant results were found for ill parents or co-parents regarding the question “I am satisfied with the time I spend together with my family.” However, many families mentioned in the interviews that they prioritized doing fun activities together as a family more following their participation in FTI. A father whose wife died during the intervention said: “All of a sudden, there are a lot of other things that are much more important than what we were focused on before, specifically family cohesion.” Being satisfied with the time spent together and choosing to prioritize spending time together are not the same thing, but both may speak to the importance and quality of family relationships.

At follow-up one, approximately half of ill parents and co-parents reported that their relationship with their partner and/or child(ren) had improved. Parent responses during the interviews elaborated on these findings, as parents shared examples of strategies their family used to build and maintain healthy family relationships. Ill parents described how they and their co-parents had started spending extra one-on-one time with their children and especially step-children, to ensure a healthy relationship was in place before the parent died and to build happy memories. According to an ill father: “the children have been asking for is more alone time with me. That we do things together this summer. This may be the last summer we have together where I will have the energy.” Parents also stated that participating in FTI was a good reminder to listen to their children’s concerns and that communication strategies they learned from FTI helped them talk with their children more openly and solve problems. The ill father explained: “We do things together that they want to do. My daughter and I have gone for coffee together. Me and my oldest son go fishing.”

### Increased security and reduced worry about the future

While there were no statistically significant results for ill parents or co-parents regarding the question “I am worried about someone in my family,” the majority of ill parents and co-parents reported that they were less worried in general during the interviews. Several of the ill parents said that they felt more secure knowing their family members had a better understanding of each other’s perspectives and that they were confident that their family would be okay after their death. An ill father stated:

I have my wife, she will always be with me as long as I live, and my children too ... but despite that, I still want this support because it feels reassuring for me ... it’s nice you know ... that I get support, that I can feel secure.

Healthy parents similarly expressed that they were more confident that their children would be open and honest about how they felt leading up to and following the parent’s death. As a part of the intervention, families also received help to arrange extra therapy or counseling as well as communication with their child’s school. Parents appreciated that the interventionists helped them apply for stipends from charities to aid the family financially.

### Discussion

This is the first study to examine the impact of FTI on parents in specialized palliative home care. During interviews, parents stated that family communication improved as a result of participating

in FTI, as family members learned new communication strategies which facilitated more open sharing of their thoughts and feelings. Increased open communication helped family members gain a better understanding of each other’s perspectives. Parents also reported that their relationships with their partner and children had improved as they now shared several strategies for maintaining family relationships. Parents expressed that they felt more secure and less worried regarding their family’s future following participation in FTI, and ill parents stated that they gained a sense of security that things would work out for their bereaved family following their death. Each of the four categories in this study seemed to be related to FTI key concepts. Our results are similar to studies of FTI in other contexts (Beardslee et al., 1992, 1993, 1998, 2003; Focht and Beardslee, 1996; Bugge, 2009), indicating that FTI is likely equally beneficial to families when conducted in a specialized palliative home care setting.

Parents reported that they shared more illness-related information within their family following participation in the intervention, thereby increasing family members’ knowledge regarding the illness, reactions, symptoms, and treatment which is related to the FTI key concept “bringing knowledge about the illness.” This is the main goal of FTI and is thought to be facilitated by the use of psycho-education, which increases family members’ knowledge and understanding of the illness, together with the application of narrative theory, which provides each family member with the opportunity to share their unique perspective and create a shared family history (Focht and Beardslee, 1996; Beardslee et al., 1998). Similarly, earlier studies of FTI found that parents reported increased understanding of the illness, reduced family conflict, learned how to support their children, and increased open communication about the family’s situation (Beardslee et al., 1992, 1993, 2003; Bugge et al., 2009).

The results related to the category *Talking together as a family* exemplified how the FTI key concept “breaking the silence together as a family” manifested during the intervention, as parents stated that family communication had improved as a result of learning new communication strategies and practicing speaking more openly during FTI. While the main focus of FTI is on learning to communicate about the parent’s illness, the family also learns to talk about other types of struggles, conflicts, or worries they may be having, most of which are related to or caused by factors surrounding the parent’s illness (Beardslee et al., 2003). Family members make active choices regarding “breaking the silence together as a family” and decide, consciously or subconsciously, what they will and will not talk about and how openly they want to share with each other. Learning to communicate more openly may be beneficial to families, as open communication between the two parents has been shown to promote healthy adjustment since it counteracts loneliness and isolation and builds a fuller, richer relationship that the co-parent can draw strength from (Bosticco and Thompson, 2005). Open communication between the surviving parent and children has been associated with better psychological health in children and adolescents following the ill parent’s death (Weber et al., 2019).

By learning to “break the silence” and speak more openly about the family situation, family members gained a better understanding of each other’s perspectives which, according to participating parents, helped improve family communication and relationships. This is related to the FTI key concept of “sharing a history together.” FTI was specifically designed to achieve this (Beardslee et al., 1992). Bugge et al. (2009) also found that parents had a better understanding of their children’s thoughts and

reactions, which reduced conflict and improved family communication. Family communication brings family members together, helping them learn from each other, develop self-confidence, express thoughts, feelings and beliefs, maintain rules and routines, and solve problems (Anderson, 1997; Wright and Leahey, 2013). Open communication may help reinforce healthy relationships between parents and children by forming and maintaining narratives about difficult topics, which builds trust between individuals (Quas and Fivush, 2009). Open communication has also been positively associated with family satisfaction and feeling accepted and acknowledged in one's family (Liew and Servaty-Seib, 2018). Similarly, our category *Maintaining family relationships* relates to the FTI key concept "addressing the needs of the children."

Parents felt more secure and less worried following participation in FTI and this change was still evident 1 year later. Beardslee et al. (1992) found that parents' illness-related concerns were reduced following FTI and that parents reported a sense of reassurance regarding the parent's affective illness. Similarly, children who participated in FTI reported that increased knowledge of the parent's illness reduced their worry (Bugge et al., 2008; Eklund et al., 2020a). Several of the ill parents in our study stated that they gained a sense of security thanks to feeling that things would be okay. These results may be related to the FTI key concept "continuing the family dialogue, moving on and facing the future."

### Strengths and limitations

A strength was the use of a convergent mixed-method design and analysis which provided a deeper understanding of the results, as the qualitative results expanded upon the statistically insignificant results which were likely affected by the small sample size. For several of the categories, the qualitative results indicated improvements in family communication, relationships and feelings of security as well as reduced worry. However, the quantitative results were most often not significant which may have been caused by a lack of sensitivity of the study-specific questionnaire. The wording of the single-item questions did sometimes differ from how the participants expressed themselves during the interviews which may have affected the ability of the mixed-method analysis to confirm or disprove all the quantitative results using the qualitative results. Using validated instruments rather than single-item questions may have increased the statistical significance of the quantitative results and may have provided more specific information on how or to what degree family communication or relationships improved following FTI. Due to the small homogeneous sample, further testing of FTI in specialized palliative home care is needed before results can be generalized. However, this study provides a good foundation for future studies by helping to determine the weaknesses of the study methodology and design which should be improved while identifying key results warranting further exploration.

### Implications for clinical practice

Our results indicate that FTI would be beneficial for families with children when a parent is being cared for in specialized palliative home care. How the intervention would be delivered and by whom would need to be determined based on available resources and the structure of the local healthcare system. That being said, where the intervention takes place, the length of each session and amount of time between sessions are flexible making FTI

potentially easier to implement than other interventions with stricter parameters. FTI can also be delivered by a wide variety of professionals including but not limited to social workers, deacons, nurses, psychotherapists, mental health counselors, and doctors.

### Conclusion

This study contributes new evidence that FTI likely improves family communication and relationships and increases perspective-taking in families with dependent children when a parent is cared for in specialized palliative home care. The finding regarding the parents' increased feelings of security and reduced worry supports prior evidence that FTI reduces worry and provides reassurance regarding illness-related concerns. Furthermore, this study adds to the evidence that FTI may help to improve family communication and relationships.

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