

# **Death Studies**



ISSN: 0748-1187 (Print) 1091-7683 (Online) Journal homepage: https://www.tandfonline.com/loi/udst20

# The grief and communication family support intervention: Intervention fidelity, participant experiences, and potential outcomes

Megan Weber Falk, Anette Alvariza, Ulrika Kreicbergs & Josefin Sveen

To cite this article: Megan Weber Falk, Anette Alvariza, Ulrika Kreicbergs & Josefin Sveen (2020): The grief and communication family support intervention: Intervention fidelity, participant experiences, and potential outcomes, Death Studies, DOI: 10.1080/07481187.2020.1728429

To link to this article: <a href="https://doi.org/10.1080/07481187.2020.1728429">https://doi.org/10.1080/07481187.2020.1728429</a>

9	© 2020 The Author(s). Published with license by Taylor & Francis Group, LLC
	Published online: 19 Feb 2020.
	Submit your article to this journal 🗷
hh	Article views: 582
Q <sup>1</sup>	View related articles 🗗
CrossMark	View Crossmark data 🗷



#### ARTICLE

OPEN ACCESS Check for updates



# The grief and communication family support intervention: Intervention fidelity, participant experiences, and potential outcomes

Megan Weber Falk<sup>a</sup> , Anette Alvariza<sup>a,b</sup>, Ulrika Kreicbergs<sup>a,c</sup>, and Josefin Sveen<sup>a,d</sup>

<sup>a</sup>Department of Caring Sciences, Palliative Research Centre, Ersta Sköndal Bräcke University College, Stockholm, Sweden; <sup>b</sup>Capio Palliative Care, Dalen Hospital, Stockholm, Sweden; <sup>c</sup>Department of Women and Child's Health, Karolinska Institute, Stockholm, Sweden; <sup>d</sup>Department of Neuroscience, Psychiatry, Uppsala University, Uppsala, Sweden

#### **ABSTRACT**

This study aimed to evaluate intervention fidelity and explore participants' experiences and potential outcomes after participating in the intervention. Using a pretest post-test pilot study, 10 parentally bereaved families completed the three-session manual-based intervention with a family therapist. Sessions were audio-recorded. Therapists completed an adherence checklist to assess fidelity. Assessments via questionnaires and interviews occurred at one month postintervention and via questionnaires at baseline and six months post-intervention. This study showed a high level of fidelity. The study shows preliminary evidence of the intervention's capacity to improve communication and relationships in parentally bereaved families.

Family communication has been shown to be a protective factor for children following a parent's death. Families who communicate openly about the illness and death and express their emotions have been found to have lower levels of anxiety, depression, and posttraumatic stress (Howell et al., 2016; Pettle & Britten, 1995; Sedney, Baker, & Gross, 1994; Shapiro, Howell, & Kaplow, 2014). Furthermore, higher quality communication characterized by the open sharing of thoughts, feelings, and information, as well as limited conflict, has been associated with fewer conduct or behavioral problems in parentally bereaved children and adolescents (Weber, Alvariza, Kreicbergs, & Sveen, 2019a).

Some bereaved children and families may need professional support to cope with their grief because the death of a parent is one of the most traumatic events a child or adolescent can experience. Parentally bereaved children often experience more psychiatric problems, prolonged grief, higher levels of drug and alcohol use, increased anxiety, lower self-confidence, and more selfharm behaviors than non-bereaved peers (Ayers et al., 2014; Bergman, Axberg, & Hanson, 2017; Bylund Grenklo et al., 2013; Ellis, Dowrick, & Lloyd-Williams, 2013; Pfeffer, Karus, Siegel, & Jiang, 2000; Sandler et al., 1992; Spuij, van Londen-Huiberts, & Boelen, 2013; Worden, 1996; Worden & Silverman, 1996).

Interventions for parentally bereaved children, include group, family, and individual therapy, as well as support groups. Currier, Holland, and Neimeyer (2007) noted a lack of consensus regarding what should be included in interventions for parentally bereaved children, but found that relatively brief interventions might prevent psychological health problems in children and adolescents. These findings were supported in a review by Bergman et al. (2017); these authors further suggested that supportive programs where the parent and children meet with a therapist together are important, as it is often the first time they talk about the loss and their emotions with other family members. Chen and Panebianco (2018) conducted a review of interventions for preschool aged children who had experienced the death of a parent, sibling, or other family member. All of the 17 studies reviewed had a small sample size and the majority of interventions, regardless of theoretical orientation, included some type of psychoeducation. Interventions included play therapy, expressive arts therapy, cognitive behavioral therapy, and family therapy, with the goal of helping parents and children normalize grief experiences, express grief, develop coping skills, improve parent-child communication, and improve family relationships. Quantitative results from these studies were usually inconclusive with qualitative data providing a positive narrative from participating parents, which tended to support intervention effectiveness and meaningfulness.

Bergman, Axberg, and Hanson (2017) reviewed interventions focused on parentally bereaved children who were school aged up to 18 years. Group interventions, family interventions, parental guidance, and camp activities of varying theoretical orientations tended to result in small effect sizes, possibly due to the preventive nature of the interventions. Despite the small effect size in most of these studies, the participating children reported that the interventions had been meaningful for them. Of the 17 studies included in this review, 15 were randomized controlled studies. The most well studied intervention was the Family Bereavement Program (FBP), which is a group based intervention where parent and child groups meet in parallel for 12 sessions. The FBP has been followed-up longitudinally for 15 years. Randomized controlled studies of the FBP have resulted in moderate-large effects on children's grief symptoms, health, behavior, and self-esteem as well as improved caregiver mental health (Sandler et al., 2003; Sandler et al., 2018).

The present study tested the manual-based Grief and Communication Family Support Intervention, which aims to reinforce open family communication, provide psychoeducation on grief, and promote healthy adaptation to bereavement. This intervention was developed to fill the gap in services for parentally bereaved children in Sweden. Bereavement support services for children and adolescents are underprovided in Sweden, likely due to a lack of clear divisions of responsibilities and lack of clear routines regarding the implementation of bereavement support interventions.

Approximately half of bereaved children and adolescents in a Swedish report felt they were in need of some type of help or support (Bergh Johannesson et al., 2014; Bergman & Hanson, 2014). In some parts of Sweden, the Swedish Church and other nonprofit organizations offer bereavement support (Hansson, 2012). These efforts are often poorly structured, have strict rules regarding who can participate (e.g., child's age, time since death) and are not evidence based bereavement support interventions. As is the case in many countries, when the parent has been cared for in a palliative care setting, children are more likely to have access to bereavement support than in other health care settings due to palliative care's emphasis on caring for the whole family (Breen, Aoun, O'Connor, & Rumbold, 2014; Payne, 2010; Radbruch & Payne, 2010). Furthermore, mental health care for

children and adolescents in Sweden is divided into specialized and primary care with each level of service prioritizing the most severe cases with which they are presented. This causes children and adolescents in need of preventive care and those exhibiting mildmoderate concerns, such as grief, often fall through the cracks and not receive the care they need (Siren, Wicks, Lindberg, & Dalman, 2018).

In a previous study (Weber, Alvariza, Kreicbergs, & Sveen, 2019b), we described how the Grief and Communication Family Support intervention was adapted from the group based FBP (Ayers et al., 2014; Sandler, Ayers, & Romer, 2002; Sandler et al., 2003) to a family setting. In short, modules related to grief and family communication were taken from the group-based FBP intervention manual and modified by combining complementary parent and child exercises into one family oriented module. Like the FBP, the Grief and Communication Family Support Intervention aims to reinforce open family communication, provide psychoeducation on grief, and promote healthy adaptation to bereavement. The aims of the current study were to evaluate intervention fidelity and to explore family members' experiences and potential outcomes after participating in the Grief and Communication Family Support Intervention.

# **Methods**

# **Grief and communication family support** intervention

The Grief and Communication Family Support Intervention comprises three 90 min sessions with a family therapist to talk about the family's current situation, learn about grief and communication, and practice communication strategies. Family therapy methods which focus on family relationships and emotional processing through family discussion are used together with cognitive behavioral methods such as skills training and roleplay. The contents of each session are shown in Table 1 and are described in more detail in a previous study (Weber et al., 2019b). Session one focuses on establishing a therapeutic alliance and providing the family with psychoeducation on grief and communication. Session two comprises skills training modules including "I" messages, sharing feelings, and active listening. In session three, the family members learn a strategy for problem-solving and use the other skills they have practiced in an exercise where each family member shares a memento from the deceased parent with the rest of the family and the therapist. The sessions are manual-based and

#### **Table 1.** Session modules.

Session 1

The family's new circumstances: The therapist learns about the family's situation, what the family would like to improve, what the family is happy or unhappy with as regards their daily life, relationships, and communication, and establishes a therapeutic alliance.

Psychoeducation about grief: The therapist provides the family with information about common grief reactions using a brochure.

Psychoeducation — what is "good" communication: The therapist presents a clear overview of strategies which can contribute to good communication, such as using "I" messages and active listening.

Psychoeducation — what can make communication more or less difficult: The parents and children identify barriers to good communication and to identify strategies which can ease communication in their family.

Summary of session 1: The therapist and family members summarize what was discussed and what the family members learned in the first session.

#### Session 2

Reflection from session 1: The therapist summarizes what was talked about in the previous session and families can ask questions or give feedback. Hiding feelings: The family is asked to provide examples of feelings which people generally may try to hide, using feeling cards provided by the therapist. Sharing positive feelings: Parents and children are asked to identify feelings, talk about feelings, and identify positive effects of sharing feelings with

"I" messages and active listening: Family members practice clearly and concisely expressing their thoughts and feelings using "I" messages and active listening skills.

Family time: The therapist explains why spending time together as a family doing mutually enjoyable activities is important for bereaved families. The family then discusses their thoughts and feelings on spending time together and brainstorm fun activities that they can do together.

Summary of session 2: The therapist and family members summarize what was discussed and what the family members learned in the second session.

Reflection from session 2: The therapist summarizes what was talked about in the previous session and families can ask questions or give feedback. Families tell the therapist about how family time worked for them during the previous week.

Problem-solving: The therapist introduces a method for problem-solving which the parent and children then practice.

Memento: Each person shares a memento with the other family members and therapist. Parents are asked to summarize what their children said about their mementos, thereby showing their children that they have listened. Family members practice combining all the strategies they have learned by sharing their thoughts and feelings and using "I" messages and active listening.

Family discussion: The family talks about their grief, including positive and negative changes that have occurred in the family since the parent's death. The therapist normalizes these changes and helps the family members see that they have the necessary coping skills to handle these changes. The family should identify how their grief and/or communication may have changed during the intervention. The therapist should point out similarities and differences from the grief discussion in session 1.

Conclusion and summary of the intervention: Family members are asked to summarize what they have learned as well as what communication strategies they found to be helpful or useful. The family discusses which strategies they would like to continue using. The therapist gives the family feedback regarding their progress and thanks them for participating.

include the surviving parent and at least one child age three years or older. The adaptation of the intervention is described in Weber et al. (2019b) and was performed by the research group and two therapists who acted as intervention providers in this study.

#### Design

We used a pretest post-test pilot study in which all participants were offered three sessions with a family therapist. Due to the small sample size, a mixed methods design was chosen where the use of quantitative and qualitative methods was predetermined and planned prior to the start of data collection. Quantitative data were collected via questionnaires and followed up with qualitative interview data. These were interpreted and analyzed systematically, leading to a more complete understanding and increased credibility of the results (Creswell & Plano Clark, 2011).

# **Participants**

Participants were recruited from a questionnaire study among surviving partners and children of individuals who died of cancer in 2013, 2014 or 2015. Deceased persons aged 25-65 years were identified using the Swedish National Causes of Death Register and were then linked

to surviving children using the Multi-Generational Register at Statistics Sweden. Children were between the ages of 1 and 18 years at the time of their parent's death. If the deceased had been living in Stockholm county with a partner, the surviving partner and children were eligible for the study. Participating families were required to reside in Stockholm county at the time of data collection and speak and read/write in Swedish.

Five mothers and five fathers with a mean age of 48.5 years (Table 2) and a mean time since loss of 3.1 years at baseline elected to participate in the current study along with their children, who had a mean age of 11.42 years (n = 14; Table 3). There were no inclusion or exclusion criteria with regard to mental or physical illness, or having previously sought counseling, therapy, or any other type of psycho-social support and, as a result, participating families had sought prior professional help to varying degrees (Tables 2 and 3).

# **Procedure**

The study was registered at clinicaltrials.gov under the Unique Protocol ID DRN 2016/1192/31/1 and approved by the Regional Ethics Committee of Stockholm. Parents completed a baseline questionnaire for themselves and for each of their children. At the

**Table 2.** Parent demographic characteristics (n = 10).

Item/Question	n
Gender	
Female	5
Male	5
Educational level	
Primary school	1
High school	1
College/university	8
Employment status	
Working	8
Studying	1
Disability leave	1
Current marital status	
Married	0
Living with partner	1
In a relationship	2
Single	7
Have you been on sick leave or disability leave due to your partner's illness or death?	
No	3
Yes, during my partner's illness	5
Yes, after my partner died	5
Have you been home with your child (parental leave) due to your partner's illness or death?	
No .	3
Yes, during my partner's illness	5
Yes, after my partner died	7
Have you ever sought treatment for anxiety?	
Yes, before my partner was sick	1
Yes, during my partner's illness	3
Yes, after my partner died	4
No, never	6
Have you ever sought treatment for depression?	_
Yes, before my partner was sick	2
Yes, during my partner's illness	2
Yes, after my partner died	3
No, never	6
Have you ever been on sick leave for psychological health problems such as anxiety, depression, or stress?	1
Yes, before my partner was sick	1
Yes, during my partner's illness	5 5
Yes, after my partner died	
No, never	4
My partner had: Skin cancer	1
	1
Stomach/colon cancer	3
Pancreatic cancer Sarcoma	1 2
Sarcoma Lymphoma	1
Ventricular cancer	1
	1
Acute leukemia	I

end of the parent questionnaire, a brief description of the intervention study was given and parents could respond that they would like to participate, would like more information, or declined participation. Parents who indicated that they were interested in participating or would like more information regarding the intervention were sent an information letter via email. The research team contacted these families via telephone a few days later to answer any questions about the study and to ask for verbal consent. If the family wanted to participate, their contact information was given to one of two therapists who would be conducting the intervention, based on where the family lived. The therapist contacted the family to schedule the three sessions, which were held at the therapist's private practice.

Written informed consent was collected at the beginning of the first session, at which time the therapists also asked each family if their sessions could be audio-recorded so that the research team could assess intervention fidelity. Adolescents aged 15 years or older were required to consent to participation and all children were required to assent to participation in accordance with Swedish law. Families could participate even if they declined to have their sessions recorded. The therapists filled in a self-report checklist for each session, indicating which modules from the manual they had completed during that session. They could add notes about each session, for example what had worked well, what prevented them from completing a specific module, or specific issues that arose which needed to be addressed before proceeding with

**Table 3.** Child demographic characteristics (n = 14).

Item/Question	n
Gender	
Female	5
Male	9
School/employment School/employment	
Preschool	2
School	11
Working	1
Missed school/work due to parent's illness or death	
During the parent's illness	4
After the parent's death	4
Never	10
Does your child typically share their thoughts and feelings with someone?	
No, I do not believe they do	4
Yes, I believe they do	10
Has your child ever been to a counselor, therapist, psychologist, or participated in a support group?	
Yes, before my partner was sick	0
Yes, during my partner's illness	1
Yes, after my partner died	10
No, never	4

the manual-based modules. The first author listened to each recorded session and completed an independent adherence checklist which was then compared with the therapist's self-report checklist.

Parents completed one-month follow-up questionnaires for themselves and each of their children and were also invited to an interview in which their children were welcome to participate. Nine of the ten families participated in the one month follow-up, with four families completing the one-month follow-up questionnaire, one family participating in an interview, and four families completing the questionnaire and participating in an interview.

Parents were again asked to complete a follow-up questionnaire for themselves and each of their children six months post intervention at which time responses were collected for 7 parents 10 children.

#### Measures

#### Adherence checklist

To evaluate intervention fidelity, an adherence checklist was created and distributed to the two therapists to be used as a self-report regarding which modules were completed during each session. Therapists were asked to fill in a checklist for each family immediately after each session.

# Baseline questionnaire

The online baseline questionnaire was comprised of demographics, questions about care, and familyrelated factors during the ill parent's last month of life (i.e., what support they had received, communication, symptom management, awareness of impending death, their experiences of the legal requirements on

healthcare staff to give age-adapted information to children), and questions about the participating parent's and children's grief and psychological symptoms following the other parent's death. Participating parents completed a parent questionnaire about their own experiences, as well as a parent-proxy questionnaire for each of their children.

# Follow-up questionnaires

A short online questionnaire regarding the three sessions with the therapist was created and distributed to participating families. Parents completed a questionnaire for themselves and one for each child. Postintervention assessment via online questionnaire occurred twice: 1 month and 6 months postintervention.

# Follow-up interviews

Parents could elect to participate in a follow-up interview one month post-intervention, with or without their children. Questions were based on the follow-up questionnaire. Specifically, families were asked to answer questions related to the intervention, including the number of sessions in which they participated; which family members were present for which sessions; how they experienced the design, content, and length of each session; what aspects of the intervention were particularly good; and if they had any recommendations for improvement. Family members were also asked about their relationship with the therapist and if they had experienced any changes with regard to communication, support, understanding, or relationships within their family after the intervention. Interviews were conducted in the family's home or at the research center and were between 45 and 120 min long. When children or adolescents were included in the interview, the family was interviewed together, with the final 15-20 min being reserved for the interviewers to speak with the child or children individually. The interviews were conducted by the first author who strived for openness in eliciting each family's unique experience. The questions were formulated based on participating children's ages and were followed up with probing questions to clarify and gain a deeper understanding. Participants could skip questions if they did not want to answer or if the questions were upsetting.

# Analytical framework

# Intervention fidelity

Fidelity was assessed using the National Institutes of Health's Behavioral Change Consortium (NIH BCC) guidelines for measuring treatment fidelity (Borrelli et al, 2005; Borrelli, 2011; Robb, Burns, Docherty, & Haase, 2011). The Grief and Communication Family Support Intervention is not considered a treatment in the sense that it is thought to cure or correct a disorder that has already developed. Therefore, we modified the domains of the NIH BCC guidelines. Fidelity was assessed across five domains: study design, provider training, delivery, receipt, and enactment. Study design is concerned with ensuring that the study adequately tests the study hypothesis and is in line with the underlying theoretical orientation and clinical processes. In our study, the number of sessions and their respective lengths and contents were predetermined and checked for consistency using audio recordings of treatment sessions. The audio recordings and adherence checklists were used to record protocol deviations or deviations from the manual. A userfriendly manual, developed together with the intervention providers, was used for all sessions.

Therapist training examines the standardization of training for all therapists providing the intervention, ensuring that they are trained using certain criteria and recruited based on specific characteristics such as education, experience, and cultural knowledge. We hired providers with similar credentials and experience to help create and provide the intervention. Both providers were present for all development and training sessions. During training, providers were able to roleplay the modules, ask questions, discuss various ways of executing each module, and give each other feedback. Provider skills and confidence were monitored throughout the study in coaching sessions with the first author. The first author listened to the audio recordings of completed sessions and provided feedback and coaching to the providers, both individually

and together. The providers engaged in peer-to-peer supervision as well.

The delivery domains encompass intervention differentiation, breaches in protocol (e.g., therapist deviations from the intervention manual or study protocol), and adherence. We assessed fidelity of treatment delivery using the adherence checklists and audio recordings. Adherence was coded as achieved or not achieved for each module and high fidelity is achieved when 80-100% of components are adhered to correctly. The number of modules completed during each session (according to the therapists' selfreport adherence checklists) was compared with the data in the adherence checklists completed by the first author. An average score for number of modules completed during each session was calculated based on the data from all 10 families. Three sessions were not recorded or were inaudible and were therefore not included in the average score calculation. Participant follow-up questionnaires and interviews were used to assess treatment delivery with regard to content and lengths of sessions, and participant feedback. Participants' responses during the interviews to the questions "What did you think about the structure, content, and length of the sessions?" and "Is there anything about any of the sessions that you would change?" were used to assess treatment delivery.

Treatment receipt and treatment enactment were monitored using participant self-reports from the follow-up interviews and questionnaires. Receipt assesses each study participant's ability and level of understanding, demonstration of knowledge, and ability to use skills taught during the intervention sessions. Enactment measures each participant's ability to apply what they learned during the sessions to their daily life and real-world situations upon completion of the intervention (Borrelli, 2011; Robb, Burns, Docherty, & Haase, 2011).

#### Data analysis

Descriptive statistics were used to describe the participants and results from the follow-up questionnaires. The follow-up interviews were conducted, transcribed, and combined with the responses to the open questions the one-month follow-up questionnaires. Inductive content analysis (Elo & Kyngäs, 2008) was used to explore family members' experiences of participating in the intervention, including satisfaction with the intervention and suggestions for improvement, as well as potential outcomes of the intervention, which were assessed via follow-up questionnaires and interviews. Open coding was conducted by the first author while reading each interview and each response to the open questions several times. Codes were recorded on a coding sheet and grouped into subcategories. Subcategories which were similar or dissimilar were collapsed into broader categories. Main categories were formed by interpreting which subcategories belonged together. Abstraction was used throughout the analysis process to form the categories.

#### Results

# **Fidelity**

# Study design

The audio recordings and therapists' notes showed that session two took longer than the allotted 90 min for all families and that session three was shorter than 90 min for all families. These were the only deviations from the study protocol.

# **Provider training**

Provider confidence increased as the therapists completed the intervention with more families. They requested less immediate feedback and were more self-assured in their choices to modify modules based on participant age or family circumstances.

#### **Delivery**

The adherence scores for each session indicate a high rate of fidelity for sessions one and three and an overall high level of fidelity for the study. There was a high level of agreement between the therapists' completed checklists and the first author's independent rating of adherence based on the session recordings (Table 4).

Based on the audio recordings and follow-up interviews, we observed the therapists successfully adapting the modules to children's age or developmental level. While some younger children struggled to concentrate for the entire 90 min, family members for the most part appeared actively engaged and participated throughout all the modules. These issues were confirmed by family members at the one-month followup interviews. A father explained:

I think two hours goes very fast but sitting and listening as a child, I understand that they thought it was long but the therapist could take us through the various topics and made sure I didn't talk too much so the children could take more space.

Similarly, a 14-year-old girl explained: "I think it was a good amount of time but some days when it's not great at school or something, then two hours or 90 min feels a little long." Children, adolescents and their parents all stated that they found the sessions to be age-appropriate, with none of the modules being too difficult or too easy. One mother said, "Maybe the therapist was able to modify it just for us!" indicating that the families felt the therapists could adapt the material included in the manual based on the children's developmental abilities.

#### Receipt

Two questions from the one-month follow-up questionnaire were used to check for receipt and showed that most parents believed they and their children had received "some" or "a lot of" information regarding each topic and that they had practiced most of the strategies during the sessions (Tables 5 and 6). During the interviews at the one-month follow-up, family members shared anecdotes of their favorite or most memorable modules from the intervention sessions. A mother of a 10-year-old boy recalled:

One thing that I especially remember was that she (the therapist) took out cards with pictures of teddy bears expressing different emotions and we could lay them out on the floor and talk about specific situations and how my son felt in that situation and he picked out some feelings and then I was asked the same question and picked completely different feelings for how I would feel in that situation.

Table 4. Treatment adherence – number of modules completed.

	Session 1: 5 Modules		Session 2:	6 Modules	Session 3: 5 Modules		
Family	Therapist report	Audio recording	Therapist report	Audio recording	Therapist report	Audio recording	
1	5	4	Not completed	6	5	4	
2	4	4	2	2	4	4	
3	5	Not recorded	6	6	3	5	
4	5	5	5	4	4	4	
5	5	3	6	6	5	4	
6	5	4	4	4	4	4	
7	5	5	5	4	5	5	
8	4	Not recorded	Only participat	ed in session 1	Only participat	ed in session 1	
9	5	5	Only participat	ed in session 1	Only participat	ed in session 1	
10	5	Not recorded	5	Not recorded	5	Not recorded	
Average score	4.8/5	4.2/5	4.7/6	4.5/6	4.3/5	4.3/5	

Table 5. Responses to the question "During the session did you/your child receive information regarding ...".

		Parent	(n = 7)		Children (n = 9)			
	Not at all	Some	A lot	Yes enough	Not at all	Some	A lot	Yes, enough
What grief is	0	2	5	0	0	5	4	0
Common grief reactions for yourself	0	3	4	0	0	4	5	0
Common grief reactions for your children	0	3	4	0	N/A	N/A	N/A	N/A
Feelings	0	2	4	1	0	2	5	2
Problem-solving	0	2	4	1	1	4	3	1
Communication strategies	0	1	4	2	1	2	4	2

#### **Enactment**

During the interviews at the one-month follow-up, family members expressed an appreciation at learning more about grief and talked about how they were using the communication strategies they had learned. Strategies that family members stated they were using in their daily communication included sharing thoughts and feelings more openly and frequently, showing appreciation for one another, "I" messages, and active listening strategies. Responses to a question in the six-month follow-up questionnaire measuring enactment indicated that "I" messages and active listening were still the two strategies most frequently used by parents and children (Table 7).

# Family members' experiences of the intervention

Parents and children stated that they would recommend the support intervention to other bereaved families. A 10-year-old girl said other children should participate because "you don't really talk about the same thing the whole time, you talk about different things so it isn't so hard, and you maybe feel a little better after too, I think." All participants thought the intervention would be meaningful or beneficial to their own family or other bereaved families with children. When asked what they thought was especially good, parents and children mentioned the following: having a therapist lead the discussion; having the opportunity to listen to each other and hear each other's experiences; giving the child/children the opportunity to learn more about grief, ask questions, and talk about their own feelings; the exercises to practice communication strategies; having someone outside the situation listen; and receiving practical examples related to grief and communication for adults, children, and adolescents. One point that parents kept bringing up was the value of being able to participate in the intervention after work or on the weekends, which is not common practice in the Swedish health care system.

Participants reported improved relationships, having new knowledge, and an opportunity to talk together during the one-month and six-month followup assessments. One parent reported that their relationship to their child was significantly improved and five reported that their relationship to their child was better. A father wrote in his questionnaire "It feels like we have become stronger together and know that we can talk to each other when we need to." Children and adolescents also stated in the interviews that they felt more comfortable or confident coming to their parent with a problem or expressing negative emotions such as sadness or worry.

Families not only learned new communication skills, but reported gaining new knowledge regarding other family members' individual experiences. As they discussed everything they had experienced surrounding the parent's illness and death, family members were able to share their unique experiences and important information came up that other family members had not been aware of previously. A 14year-old girl described:

It was good that we could talk about how it was when she died and after. For example, Dad thought I was angry with Mom, which I wasn't, and I've tried to explain to him many times, but during the sessions he still thought that and those types of things I got

Family members gave many examples of individual experiences which were shared during the sessions, such as anxiety or guilt, of which the rest of the family had not been aware previously. These types of revelations helped in opening up communication within the family.

Family members also stated that the three sessions allowed the family to sit and talk together to create a shared family memory. A father to a 14-year-old daughter and 12-year-old son said: "I think it was good because we could sit down together, we had never sat together and discussed what actually happened. I think that was the biggest effect, that we created a shared memory around it." Having the opportunity to talk in a safe and structured environment was the first time that most of the participating families openly discussed the intimate details of the deceased parent's illness and death and the family's experiences in the years following the death.

Table 6. Responses to the question "During the session did you/your child have the opportunity to practice ...

		Parent	Parents $(n=7)$			Childre	Children $(n=9)$	
	Not at all	Some	A lot	Yes enough	Not at all	Some	A lot	Yes, enough
Identifying your own grief reactions	-	4	2	0	0	4	5	0
Identifying other family members' grief reactions	0	4	3	0	0	2	4	0
Processing your emotions	-	4	2	0	2	m	4	0
Talking about the grief you feel	0	3	3	_	0	4	4	_
Sharing feelings	0	3	4	0	-	m	4	_
Solving problems in a positive way	-	2	3	_	-	m	4	_
Using communication strategies such as active listening or "I" messages	0	2	4	1	2	1	5	1

Family members also offered suggestions for improvement. One parent thought an introductory session with just the parent would have been helpful. Several parents wished they had received written information about the communication strategies covered during the sessions so that they could review the exercises at home. A main topic of discussion for all the families was how long after the death the sessions should be offered, with most participants agreeing that two years after the parent's death would be the best time. A 21-year-old daughter stated "I would have wanted to have these sessions earlier. Three years is a little too long to hold in all of your feelings and not talk with a professional." Several participants also stated that one year after the parent's death would have been too soon, as they had experienced the first year of bereavement as chaotic and overwhelming.

#### Discussion

This pilot study showed evidence that the Grief and Communication Family Support Intervention had high levels of fidelity, which enhances the internal validity of the intervention (Borrelli, 2011). Communication is considered to be a protective factor for parentally bereaved children's psychological health (Howell et al., 2016; Shapiro, Howell, & Kaplow, 2014). The length of the intervention, three sessions, appeared to be adequate and acceptable to participants. Furthermore, these three sessions led to reported improvements in communication and family relationships, which supports previous findings that brief interventions may be effective with parentally bereaved families (Bergman et al., 2017). Participants reported that they learned new communications skills such as "I" messages, active listening, and openness in talking about feelings. In providing preliminary evidence for improving family communication and relationships in parentally bereaved families, the Grief and Communication Family Support Intervention may be a possible solution to the lack of bereavement and grief support interventions in Sweden.

We assessed the fidelity of the intervention using several strategies, which we categorized and reported according guidelines. to the NIH BCC These guidelines provided a useful structure to ensure that fidelity was being assessed as thoroughly as possible. Robb et al. (2011) also used the NIH BCC guidelines to categorize strategies for assessing fidelity in their study and reported that the guidelines were easy to use, although some of the five domains were more ambiguous than others. According to Robb

Table 7. Responses to the question "Do you use any of the strategies included in the three sessions in your family today?".

		Parents	(n = 7)		Children ( <i>n</i> = 9)			
	Never	Sometimes	Often	Very often	Never	Sometimes	Often	Very often
Identifying your own grief reactions	0	7	0	0	4	6	0	0
Identifying other family members' grief reactions	1	5	1	0	3	6	1	0
Processing your emotions	0	4	3	0	2	6	2	0
Talking about the grief you feel	0	4	3	0	2	5	1	2
Sharing feelings	0	3	3	1	1	6	2	1
Problem-solving	1	4	2	0	2	6	2	0
Active listening	0	2	5	0	1	6	3	0
"I" messages	1	2	4	0	1	7	2	0

et al. (2011), enactment was the most ambiguous of the five domains. In our study, we found enactment to be very clear and easy to measure. Resnick et al. (2005) also stated that enactment was the most difficult aspect of fidelity to measure, as the focus of enactment when assessing fidelity should be on participants' ability to implement the skills needed for them to achieve study outcomes rather than simply measuring study outcomes. In our study, communication skills were taught during the intervention and participants reported using these skills after the intervention, rather than their sense of improved communication. It is possible that the NIH BCC guidelines may be interpreted or applied differently based on the type of intervention being conducted or that enactment, specifically, may be more or less difficult to assess depending on the type of intervention studied.

The therapists were able to adapt the modules according to children's ages, which may have affected the number of modules they were able to complete. Tailoring manualized interventions to the needs of an individual client is crucial and therapists who use manual based interventions need to maintain a balance of clinical flexibility (i.e., what is best for their client) with fidelity to the intervention protocol (Addis, Wade, & Hatgis, 1999). Similar to our study, Scheeringa, Weems, Cohen, Amaya-Jackson, and Guthrie (2011) found that young children needed more time to complete certain tasks or modules, but could complete them with extra time and guidance. Furthermore, they were able to understand complex concepts related to the intervention through the use of cartoons, whereas older children were able to understand the same concepts through discussion or written information. This is similar to our use of "feeling cards" to help children understand and express emotions during the sessions. Furthermore, families reported that the intervention improved relationships between family members and gave them an opportunity to talk together as a family. This is similar to the results of Henoch, Berg, and Benkel (2016), who found that participating in support groups

following the death of a parent facilitated family conversation and led to an improved family climate with increased openness when talking about the deceased parent and sharing painful emotions. Bereavement support groups and other types of supportive bereavement interventions often help to reestablish trust within a family while opening lines of communication, which brings the parent and child together and creates closeness (Werner-Lin & Biank, 2012).

This study has several strengths and limitations. The use of audio recording and independent evaluation of adherence by the first author was a strength, enhancing fidelity with regard to study design and delivery, although some might see this a weakness due to bias. The first author did make a subjective assessment of the quality of delivery which influenced the first author's rating of adherence. Still, having both the therapists and the first author assess adherence helped to ensure internal validity and will be useful in replicating the study with a larger sample. Another strength was the adaptability of the manual to children of different ages. Furthermore, the use of two therapists at separate private practice settings helped to ensure that the results were not due to the specific characteristics of a single therapist or setting. A less subjective assessment of quality of delivery should be included in future studies.

While parent-proxy questionnaires were used as the main source of data collection, parents were asked and encouraged to complete the proxy questionnaires together with their child. However, there is no way to know if this was done or not. For this reason, parents were also asked to allow their children and adolescents to participate in the one-month follow-up interviews which some did. While it is important to note that we do not consider one family member to be an adequate proxy for the entire family (Breen et al., 2019; Handel, 1997), the parent's judgement regarding their child's emotional readiness to participate in data collection must also be respected. Adolescents were also asked to complete a self-report questionnaire at baseline, one-month, and six-month follow-up but



very few completed the follow-up questionnaires. While the use of parent-proxy is in several ways a limitation, the usefulness of parent-proxy reports has been shown with regards to younger children (Erhart, Ellert, Kurth, & Ravens-Sieberer, 2009; Theunissen et al., 1998); however, a multidimensional assessment approach with multiple informants would have been more valuable in this study.

Several validated instruments which assess various aspects of psychological health and communication were included in the questionnaires. A complete overview of these instruments is outside the scope of this study. However, given the high response rate at baseline, one-month and six-month follow-up for parent and parent-proxy reports, we can assume that parents were able and willing to complete these instruments. Reasons for the adolescents not completing the follow-up questionnaires are unknown. Finally, due to the small and homogenous sample, our findings may not be generalizable. Therefore, larger studies that include a control group are needed to confirm the results of this study before any conclusions about the effects of the intervention can be made.

#### **Disclosure statement**

No potential conflict of interest was reported by the author(s).

# **Funding**

This work was supported by The Kamprad Family Foundation, grant #20150044, Gålö Foundation, and The Erling-Persson Family Foundation.

# **ORCID**

Megan Weber Falk http://orcid.org/0000-0003-2786-1997 Josefin Sveen (b) http://orcid.org/0000-0002-5523-8126

#### References

- Addis, M. E., Wade, W. A., & Hatgis, C. (1999). Barriers to dissemination of evidence-based practices: Addressing practitioners' concerns about manual-based psychotherapies. Clinical Psychology: Science and Practice, 6(4), 430-441. doi:10.1093/clipsy.6.4.430
- Ayers, T. S., Wolchik, S. A., Sandler, I. N., Twohey, J. L., Weyer, J. L., Padgett-Jones, S., ... Kriege, G. (2014). The Family Bereavement Program: Description of a theorybased prevention program for parentally-bereaved children and adolescents. Omega - Journal of Death and Dying, 68(4), 293-314. doi:10.2190/OM.68.4.a
- Bergh Johannesson, K., Bondjers, K., Arnberg, F., Nilsson, D., Ängarne-Lindberg, T., & Rostila, M. (2014). Utvärdering av barntraumateamet i Norrköping

- [Evaluation of the child trauma team in Norrköping]. Retrieved from https://www.anhoriga.se/Global/BSA/ Dokument/Rapporter\_kunskaps%C3%B6versikter/BSArapport\_2014-2\_Barntrauma.pdf.
- Bergman, A. S., Axberg, U., & Hanson, E. (2017). When a parent dies-a systematic review of the effects of support programs for parentally bereaved children and their caregivers. BMC Palliative Care, 16(1), 39.
- Bergman, A., & Hanson, E. (2014). Barn som anhöriga när en förälder avlider [Children as next of kin when a parent dies]. (Nka Barn som anhöriga 2014:1). Kalmar: Nationellt kompetenscentrum anhöriga [National Competens Center for Next of Kin].
- Borrelli, B. (2011). The assessment, monitoring, and enhancement of treatment fidelity in public health clinical trials. Journal of Public Health Dentistry, 71, S52-S63. doi:10.1111/j.1752-7325.2011.00233.x
- Borrelli, B., Sepinwall, D., Ernst, D., Bellg, A. J., Czajkowski, S., Breger, R., ... Orwig, D. (2005). A new tool to assess treatment fidelity and evaluation of treatment fidelity across 10 years of health behavior research. Journal of Consulting and Clinical Psychology, 73(5), 852-860. doi: 10.1037/0022-006X.73.5.852
- Breen, L. J., Aoun, S. M., O'Connor, M., & Rumbold, B. (2014). Bridging the gaps in palliative care bereavement support: An international perspective. Death Studies, 38(1), 54-61. doi:10.1080/07481187.2012.725451
- Breen, L. J., Szylit, R., Gilbert, K. R., Macpherson, C., Murphy, I., Nadeau, J. W., ... Wiegand, D. L. (2019). Invitation to grief in the family context. Death Studies, 43(3), 173-182. doi:10.1080/07481187.2018.1442375
- Bylund Grenklo, T., Kreicbergs, U., Valdimarsdottir, U., Steineck, G., Nyberg, T., & Furst, C. J. (2013). Self-injury in teenagers who lost a parent to cancer: A nationwide, population-based, long-term follow-up. JAMA Pediatrics, 167(2), 133. doi:10.1001/jamapediatrics.2013.430
- Chen, C. Y.-C., & Panebianco, A. (2018). Interventions for young bereaved children: A systematic review and implications for school mental health providers. Child & Youth Care Forum, 47(2), 151-171. doi:10.1007/s10566-017-9426-x
- Creswell, J. W., & Plano Clark, V. L. (2011). Designing and conducting mixed methods research (2nd ed.). Los Angeles, CA: Sage.
- Currier, J. M., Holland, J. M., & Neimeyer, R. A. (2007). The effectiveness of bereavement interventions with children: A meta-analytic review of controlled outcome research. Journal of Clinical Child & Adolescent doi:10.1080/ Psychology, 36(2), 253-259. 15374410701279669.
- Ellis, J., Dowrick, C., & Lloyd-Williams, M. (2013). The long-term impact of early parental death: Lessons from a narrative study. Journal of the Royal Society of Medicine, 106(2), 57-67. doi:10.1177/0141076812472623
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. Journal of Advanced Nursing, 62(1), 107-115. doi:10.1111/j.1365-2648.2007.04569.x
- Erhart, M., Ellert, U., Kurth, B.-M., & Ravens-Sieberer, U. (2009). Measuring adolescents' HRQoL via self reports and parent proxy reports: An evaluation of the psychometric properties of both versions of the KINDL-R



- instrument. Health and Quality of Life Outcomes, 7(1), 77. doi:10.1186/1477-7525-7-77
- Handel, G. (1997). Family worlds and qualitative family research. Marriage & Family Review, 24(3-4), 335-348. doi:10.1300/J002v24n03 06
- Hansson, E. (2012). Barn till föräldrar som avlider. Enheten för Vägledning 2. [Children of Parents who Die. Center for Guidance 2].
- Henoch, I., Berg, C., & Benkel, I. (2016). The shared experience help the bereavement to flow: A family support group evaluation. American Journal of Hospice and Palliative Medicine, 33(10), 959-965. doi:10.1177/ 1049909115607204
- Howell, K. H., Barrett-Becker, E., Burnside, A., Wamser-Nanney, R., Layne, C., & Kaplow, J. (2016). Children facing parental cancer versus parental death: The buffering effects of positive parenting and emotional expression. Journal of Child and Family Studies, 25(1), 152-164. doi: 10.1007/s10826-015-0198-3
- Payne, S. (2010). White Paper on improving support for family carers in palliative care: Part 1. European Journal of Palliative Care, 17(5), 238-245.
- Pettle, S., & Britten, C. (1995). Talking with children about death and dying. Child: Care, Health and Development, 21(6), 395-404. doi:10.1111/j.1365-2214.1995.tb00770.x
- Pfeffer, C. R., Karus, D., Siegel, K., & Jiang, H. (2000). Child survivors of parental death from cancer or suicide: Depressive and behavioral outcomes. *Psycho-oncology*, 9(1), 1–10. doi:10.1002/(sici)1099-1611(200001/02)9:1<1:: aid-pon430>3.0.co;2-5
- Radbruch, L., & Payne, S. (2010). White Paper on standards and norms for hospice and palliative care in Europe-Part 1. European Journal of Palliative Care, 17(1), 278-289.
- Resnick, B., Inguito, P., Orwig, D., Yahiro, J. Y., Hawkes, W., Werner, M., ... Magaziner, J. (2005). Treatment fidelity in behavior change research: A case example. Nursing Research, 54(2), 139-143. doi:10.1097/00006199-200503000-00010
- Robb, S. L., Burns, D. S., Docherty, S. L., & Haase, J. E. (2011). Ensuring treatment fidelity in a multi-site behavioral intervention study: Implementing NIH Behavior Change Consortium recommendations in the SMART trial. Psycho-Oncology, 20(11), 1193-1201. doi:10.1002/
- Sandler, I. N., Avers, T., & Romer, A. L. (2002). Fostering resilience in families in which a parent has died. Journal of Palliative Medicine, 5(6), 945-956. doi:10.1089/ 10966210260499195
- Sandler, I. N., Ayers, T. S., Wolchik, S. A., Tein, J.-Y., Kwok, O.-M., Haine, R. A., ... Griffin, W. A. (2003). The family bereavement program: Efficacy evaluation of a theory-based prevention program for parentally bereaved children and adolescents. Journal of Consulting and Clinical Psychology, 71(3), 587-600. doi:10.1037/ 0022-006X.71.3.587
- Sandler, I. N., West, S. G., Baca, L., Pillow, D. R., Gersten, J. C., Rogosch, F., ... Ramirez, R. (1992). Linking empirically based theory and evaluation: The family bereavement program. American Journal of Community Psychology, 20(4), 491-521. doi:10.1007/BF00937756

- Sandler, I., Gunn, H., Mazza, G., Tein, J.-Y., Wolchik, S., Kim, H., ... Porter, M. (2018). Three perspectives on mental health problems of young adults and their parents at a 15-year follow-up of the family bereavement program. Journal of Consulting and Clinical Psychology, 86(10), 845-855. doi:10.1037/ccp0000327
- Scheeringa, M. S., Weems, C. F., Cohen, J. A., Amaya-Jackson, L., & Guthrie, D. (2011). Trauma-focused cognitive-behavioral therapy for posttraumatic stress disorder in three-through six year-old children: A randomized clinical trial. Journal of Child Psychology and Psychiatry, 52(8), 853-860. doi:10.1111/j.1469-7610.2010.02354.x
- Sedney, M. A., Baker, J. E., & Gross, E. (1994). The story' of a death: Therapeutic considerations with bereaved families. Journal of Marital and Family Therapy, 20(3), 287-296. doi:10.1111/j.1752-0606.1994.tb00116.x
- Shapiro, D. N., Howell, K. H., & Kaplow, J. B. (2014). Associations among mother-child communication quality, childhood maladaptive grief, and depressive symptoms. Death Studies, 38(3), 172-178. doi:10.1080/07481187. 2012.738771
- Siren, A., Wicks, S., Lindberg, L., & Dalman, C. (2018). Uppföljning av Första Linjen Psykisk Ohälsa Barn och Unga [Follow-up of primary care for mental health problems in children and youth]. Stockholm, Sweden. Retrieved from https://www.sll.se/globalassets/bilagor-tillnyheter/2018/uppfoljning-av-forsta-linjen-psykisk-ohalsabarn-och-unga.pdf
- Spuij, M., van Londen-Huiberts, A., & Boelen, P. A. (2013). Cognitive-behavioral therapy for prolonged grief in children: Feasibility and multiple baseline study. Cognitive and Behavioral Practice, 20(3), 349-361. doi:10.1016/j. cbpra.2012.08.002
- Theunissen, N., Vogels, T., Koopman, H., Verrips, G., Zwinderman, K., Verloove-Vanhorick, S., & Wit, J. (1998). The proxy problem: Child report versus parent report in health-related quality of life research. Quality of Life Research, 7(5), 387-397. doi:10.1023/A:100880 1802877
- Weber, M., Alvariza, A., Kreicbergs, U., & Sveen, J. (2019a). Family communication and psychological health in children and adolescents following a parent's death from cancer. Omega: Journal of Death and Dying. doi:10.1177/ 0030222819859965
- Weber, M., Alvariza, A., Kreicbergs, U., & Sveen, J. (2019b). Adaptation of a grief and communication family support intervention for parentally bereaved families in Sweden. Death Studies, 1-10. doi:10.1080/07481187.2019.1661883
- Werner-Lin, A., & Biank, N. M. (2012). Holding parents so they can hold their children: Grief work with surviving spouses to support parentally bereaved children. Omega -Journal of Death and Dying, 66(1), 1-16. doi:10.2190/
- Worden, J. W. (1996). Children and grief: When a parent dies. New York, NY: Guilford.
- Worden, J. W., & Silverman, P. R. (1996). Parental death and the adjustment of school-age children. Omega -Journal of Death and Dying, 33(2), 91-102. doi:10.2190/ P77L-F6F6-5W06-NHBX