Development and Evaluation of the Grief and Communication Family Support Intervention for Parentally Bereaved Families in Sweden

Ersta Sköndal Bräcke University College has third-cycle courses and a PhD programme within the field The Individual in the Welfare Society, with two interdisciplinary subject areas, Palliative Care and Social Welfare and the Civil Society. The area frames a field of knowledge in which both the individual in palliative care and social welfare as well as societal interests and conditions are accommodated.

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Megan Weber Falk received her Bachelor of Psychology from San Francisco State University in 2008. After moving to Sweden in 2010 she focused on learning the Swedish language before completing her Master of Social Science in Psychology with an emphasis in Cognitive Behavioral Therapy. Megan has many years of experience working with children, adolescents, and families in crisis at residential treatment centers and as a school counselor. Her PhD project focused on the development and evaluation of a psycho-social support intervention for families following a parent’s death from cancer.

Support intervention for parentally bereaved families in Sweden

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Megan Weber Falk
Ersta Sköndal Bräcke University College

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Megan Weber Falk

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Abstract

Development and Evaluation of the Grief and Communication Family Support Intervention for Parentally Bereaved Families in Sweden

Megan Weber Falk

Each year in Sweden, approximately 6,900 children will have a parent diagnosed with cancer. Of all the children in Sweden born between 1990–1992, 5.6% have a parent with cancer and 1.1% of them have already had a parent die from cancer. Bereavement support is an important component in palliative care, which aims to alleviate the physical, psychological, and spiritual suffering of patients and their family members. Several, but not all families participating in the studies in this thesis came from a palliative care setting. Earlier research has shown that parentally bereaved children often experience psychological problems, physical problems, reduced self-esteem, difficulties communicating, school and behavioral problems, and/or complicated grief, with approximately 10% of parentally bereaved children experiencing some type of clinically significant psychological difficulty. Moreover, a child’s response to a parent’s death is often mediated by how their surviving parent responds to the loss. Still, support for bereaved children and families is limited in Sweden. The overall aim of this research project was to explore and describe psychological health, grief, and family communication among parentally bereaved children and surviving parents and to develop and evaluate a supportive family intervention. Four studies were conducted including an interview study exploring family communication in parentally bereaved families, a questionnaire study examining associations between family communication and psychological health in parentally bereaved children and adolescents, and the adaptation and evaluation of the Grief and Communication Family Support Intervention. Results from these four studies indicated that communication may be an important factor for adjustment following the death of a parent. Specifically, communication in some
parentally bereaved families may involve conflict, which may in turn affect child and adolescent psychological health. Results from testing the Grief and Communication Family Support Intervention indicate that it may improve family communication and relationships. Testing the Grief and Communication Family Support Intervention with larger, more diverse samples is necessary to confirm these results. The results imply that helping families find ways to adjust and adapt in healthy ways following the death of a parent, potentially through the Grief and Communication Family Support Intervention, is likely to improve psychological health and communication among bereaved family members.

*Keywords:*

Children, Parental Bereavement, Family Communication, Psychological Health
To everyone who has lost a parent during childhood.
List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


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Preface

While working as a school counselor in Sweden, I had several students who were struggling to cope with the death of a family member. I desperately searched for community resources to help these children and their families come to terms with their loss and process their grief. Child and Youth Psychiatry and pediatric primary care centers for psychological health prioritized the most severe cases and had wait times of approximately 90 days for appointments. I knew that each county employed family therapists and mental health counselors, but when I contacted them I was informed that they only worked with issues related to divorce, abuse, or addiction. Through more research, I discovered that some hospitals and the Swedish Church offered grief support groups. Unfortunately, in most cases, my students didn’t meet the strict inclusion criteria with regards to child age and time since loss. Finding a group that my students met the criteria for, at the time they wanted and needed help, was basically impossible. This left the option of private therapy, which not all families could afford. Given that the Swedish welfare state is responsible for the somatic and mental health care of adults and children – and having grown up in the United States where grief counseling is commonplace and non-profit agencies offer every type of support imaginable – I found this lack of resources to be very odd. Over time I came to realize that not only were resources lacking with regards to grief and bereavement support, but knowledge regarding grief, bereavement, and the potential effects of losing a parent during childhood seemed to be insufficient even among trained mental health professionals. When I came across an advertisement for a PhD project exploring the psychological health of parentally bereaved children and testing psychosocial interventions to help them, I immediately decided that I had to be a part of it.
## Key Terms

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<th>Concept/Term</th>
<th>Definition used in this study</th>
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<tr>
<td>Child/Children</td>
<td>Children and adolescents in the context of a parent-child relationship. In this study, all such individuals ages 3–20 years will be referred to as a child or children, unless a distinction is made.</td>
</tr>
<tr>
<td>Family</td>
<td>Parentally bereaved children and their surviving parent, as well as anyone else the family chooses to include in their self-defined concept of family, such as grandparents, new partners, step children, or pets.</td>
</tr>
<tr>
<td>Psychoeducation</td>
<td>An educational intervention provided by health care professionals to teach patients and family members factual information about specific topics, such as grief reactions.</td>
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<tr>
<td>I-message</td>
<td>A communication strategy where the speaker uses their feelings as the basis for the message. I-messages are comprised of three components: The first part of an I-message is what you feel. The second part of an I-message is what happened. The third part of an I-message is what you want (for others to just listen or to help you solve the problem).</td>
</tr>
<tr>
<td>Active listening</td>
<td>A set of behaviors including body language and eye contact which help to indicate one is listening; may also include the use of open questions to encourage the speaker to continue or to show interest in what they are saying.</td>
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1. Introduction

Each year in Sweden, more than 22,000 people die due to cancer (National Board of Health and Welfare, 2016a) and over 3,000 children under the age of 18 years lose a parent. This corresponds to 3–4% of children experiencing the death of a parent before they reach the age of 18 years (National Board of Health and Welfare, 2013). According to a Swedish report with data taken from a national database, each year, approximately 6,900 children will have a parent diagnosed with cancer (Berg & Hjern, 2016). Furthermore, of all of the children in Sweden born between 1990–1992, 5.6% have a parent with cancer and, by 2016, 1.1% of them had already had a parent die from cancer (Berg & Hjern, 2016).

The early death of a parent is among the most traumatic events that a child can experience (Breslau, Wilcox, Storr, Lucia, & Anthony, 2004). Loss of one or both parents is connected to increased vulnerability with regards to psychological problems, physical problems, reduced self-esteem and self-confidence, difficulties with communication, school and behavioral problems, and complicated grief (Bergman & Hanson, 2014; Pfeffer, Karus, Siegel, & Jiang, 2000). Berg and Hjern (2016) found that psychiatric care was 10% more common for people who had a parent die of cancer during their childhood than for those who did not. Alcohol and drug abuse were also 19% more common for people whose parent died of cancer during childhood than for the general population. Importantly, these results did not indicate that a family’s socioeconomic background affected the development of consequences related to the child’s education, work, need for psychiatric care, alcohol or drug abuse, or involvement in crime. Similarly, parentally bereaved children are at increased risk of developing internalizing and externalizing problems, which have been associated with both increased sickness absence and disability pension, as well as reduced work capacity in adulthood (Narusyte, Ropponen, Alexanderson, &
Svedberg, 2017). Both of these factors lead to increased costs for society and for the welfare state.

Furthermore, having a parent diagnosed with cancer during childhood increases the child or adolescent’s own risk of death (Chen et al., 2015). One possible explanation for this is that parentally bereaved adolescents are more likely to engage in risk-taking behaviors such as substance abuse, criminal behavior, promiscuity, and reckless driving (Ellis, Dowrick, & Lloyd-Williams, 2013; McClatchey & Vonk, 2005). Another explanation is that the death of a parent during childhood often leads to cortisol dysregulation which increases the risk for insulin resistance, cardiovascular disease, upper respiratory illness, chronic fatigue, and fibromyalgia (Luecken & Roubinov, 2012). These findings indicate that grief is not merely an individual or family problem, but a problem that affects society as a whole by increasing use of psychological and somatic health care services and, ultimately, costs.

Approximately 10% of parentally bereaved children experience some type of clinically significant psychological difficulty (Howell et al., 2016; Melhem, Porta, Shamseddeen, Walker Payne, & Brent, 2011; Worden & Silverman, 1996), which implies that many bereaved children and adolescents may be in need of psychosocial support both during their parent’s illness and following the parent’s death. Despite this, a Swedish report by Bergh Johannesson et al. (2014) found that half of bereaved children felt that they had not received any support from their school or from the health care system, even though the children thought help and support were needed.

Children and families are part of the Swedish welfare state, which is responsible for psychological and somatic health care, social services, and school-based student health teams, but when a parent dies, supportive resources are typically not available from society or the welfare state. Bereavement support is meant to be an important component in palliative care and several of the participating families in this research project came from a palliative care setting.
– although not all, as not all cancer patients receive palliative care. Furthermore, the extent to which bereavement support is offered through palliative care centers may be limited and may vary from one location to another.

With all of this in mind, it was clear to me that the needs of parentally bereaved children must be better understood and documented, so that supportive interventions can be established, tested, and implemented in Sweden. Talking about their parent’s death helps children to be able to emotionally and cognitively process the loss, have more adaptive grief, and develop higher self-esteem (Fearnley, 2015; Field, Tzadikario, Pel, & Ret, 2014). Therefore, family communication became one of the main focuses of this project and the resulting intervention. The overall aim of this research project was to explore and describe psychological health, grief, and family communication among parentally bereaved children and surviving parents and to develop and evaluate a supportive family intervention.
2. Theoretical Framework

The main focus of this research project is the psychological health and wellbeing of children and adolescents following the death of a parent to cancer. As children are always children in relation to their parents, both children and adolescents will be referred to as “child” or “children,” unless otherwise specified (i.e., when differences between young children and adolescents are discussed). Children are in many ways dependent on the surviving parent. Previous research has shown that a child’s response to a parent’s death is often mediated by how their surviving parent responds to the loss (Green & Connolly, 2009). Adverse outcomes for the bereaved child are usually reduced if the surviving parent can address and manage their own grief and maintain consistent and responsive care (Saldinger, Porterfield, & Cain, 2004; Werner-Lin & Biank, 2012). Positive parent-child relationships, attentive and sensitive parenting, and the warmth and functioning of the surviving parent have been found to be significantly associated with fewer post-death mental health problems for parentally bereaved children (Shapiro, Howell, & Kaplow, 2014; Wolchik, Tein, Sandler, & Ayers, 2006). For these reasons, bereaved children must be viewed in the context of their family environment and therefore, results regarding the surviving parents must also be considered in order to fully understand the experiences of parentally bereaved children.

Theories related to grief, attachment, systems, and meaning making have provided value to this project by helping to explain the meaning and challenges associated with the death of a parent. Furthermore, these theories help to support the knowledge and understanding gained through this research project, so that researchers, health and mental health professionals, teachers, and parents can act to support parentally bereaved children in more informed and effective ways.
2.1. Grief

Sigmund Freud was the first to describe grief (mourning) as a phenomenon separate from depression (melancholia) (Freud, 1924). Freud considered grief to be a normal and universal response to the death of a loved one, characterized by symptoms of withdrawal, dejection, reduced activity, and loss of the capacity for love. The goal of mourning, according to Freud, was simply to mourn the loss and move on. This philosophy of essentially cutting one’s losses can be seen as quite harsh from today’s perspective and is perhaps better understood in light of the catastrophic number of lost lives in World War I, which is when Freud was developing the theory behind Mourning and Melancholia. This theory influenced practices in grief therapy for most of the twentieth century (Freud, 1924; Neimeyer & Harris, 2016). Around the same time that Freud was theorizing about grief in the individual, Émile Durkheim (1912/1965) was writing about grief and society. He believed that death threatens the cohesiveness of a society. In order to cope with this threat, the deceased needs to somehow be integrated into the ongoing social system and the emotions of those in mourning need to be regulated, which is often accomplished through cultural rituals around death and grief (Durkheim, 1912/1965; Neimeyer, Prigerson, & Davies, 2002).

In the mid to late 1900s, trained medical professionals began to more thoroughly observe, decipher, and explain their insights regarding the psychological processes of dying (Clark, 1998; Neimeyer & Harris, 2016). This was the context in which Elisabeth Kübler-Ross and Ira Byock (1969) developed a five-stage model of grief which was based on the experiences of dying individuals and later applied to the grief experienced by bereaved family members, despite the fact that they had never directly studied bereaved family members’ experiences of grief. These five stages include denial, anger, bargaining, depression, and acceptance, with the main goal being to eventually let go. This became the dominant model of grief internationally and in some
medical schools was the only model of grief taught (Neimeyer & Harris, 2016). Interestingly, Freud’s idea of letting go or moving on was still central.

Throughout the 1990s and 2000s, a new wave of grief theories influenced by contextualist, constructivist, and interpretive shifts in psychology and related disciplines emerged. These new theories emphasized skepticism about the universality of predictable trajectories of emotional reactions, such as predictable phases, as well as a shift away from the assumption that detachment from the deceased is necessary. They also focused more on cognitive rather than emotional processes, increased awareness of the implications of grief for the bereaved individual’s self-identity, and placed more focus on how grief is negotiated within the family and in a wider social context (Neimeyer, 2001b).

One such theory is the dual process model of grief (Neimeyer & Harris, 2016; Stroebe & Schut, 2001). The dual process model incorporates Freud’s original idea of grief work and expands upon it by taking into account the many ways in which adaptation to grief takes place (Stroebe & Schut, 2001). This model proposes that grieving individuals oscillate between focusing on their loss and focusing on reengaging in life, also termed loss orientation and restoration orientation. Oscillation is a process of confrontation and avoidance with cognitions representing different types of meaning (Stroebe & Schut, 2001). Loss-oriented coping involves appraisal and dealing with the stressors associated with loss, such as sadness, yearning, feeling helpless, or crying, whereas restoration-oriented coping can, for example, involve engaging in necessary practical tasks and experimenting with new life roles (Stroebe & Schut, 1999).

2.2. Complicated Grief

Grief has been studied for over 100 years and a distinction has been made by most theorists between what is commonly referred to in the literature as complicated grief and normal grief, although complicated grief has gone by several names and been described in several different ways over time. Sigmund
Freud defined pathological mourning as the refusal to let go (Freud, 1924) and inspired Erich Lindemann (1944) to further study the concept. Lindemann described complicated or pathological grief as normal grief which had become distorted, being either exaggerated or apparently absent. Furthermore, Lindemann (1944) found that in cases of distorted grief, completing “grief work” could transform complicated grief into normal grief, which then resolved itself. Similarly, John Bowlby conceptualized what he called disordered mourning as either chronic mourning or the prolonged absence of conscious grieving. Chronic mourning is similar to what is currently referred to as prolonged grief or prolonged grief disorder and was considered by Bowlby to be protracted and prolonged grief where the bereaved individual may be preoccupied with thoughts of the deceased and unable to return to normal functioning for months or even years following the death of a loved one. This definition is quite similar to how prolonged grief is defined today (Fraley & Shaver, 2016).

2.3. Attachment Theory

The human responses to loss are rooted in the disruption of attachment bonds. Grief seems to be the reaction to the severing of an attachment bond, meaning that when an attachment ends, we grieve (Mallon, 2008). Therefore, without attachment, we would not feel grief (Neimeyer et al., 2002). Attachment theory helps to explain the varied responses to separation and loss of important people in our lives, such as parents and romantic partners, and there is a great deal of research showing how one’s attachment style may affect grief and communication.

2.3.1. The Basics of Attachment Theory

According to Bowlby’s attachment theory, infants become attached to adults who are consistent caregivers for some months during the period from
about six months to two years of age and who are likely to be sensitive and responsive with the infant. The attachment figure is usually a parent and sometimes another primary caregiver. The main purpose of the infant forming attachments is survival. How the attachment figure responds to the infant’s distress leads to the development of an attachment style which in turn leads to “internal working models” that help to guide the individual’s feelings, thoughts, and expectations in later relationships (Bowlby, 1969, 1973, 1980; Bretherton & Munholland, 1999). Internal working models are essentially conscious or unconscious rules and expectations on how relationships and interactions with other people should be. These rules are then used as a model for future relationships (Flanagan, 1999).

Most theorists agree that there are four distinct attachment styles: secure, anxious-avoidant and anxious-ambivalent – both of which are considered to be insecure styles – and disorganized. Attachment figures of securely attached infants tend to be responsive. Therefore, securely attached children do not worry about the availability or responsiveness of their caregiver and instead devote much of their concentration to exploration and socialization. Anxious-avoidant children, on the other hand, tend to retract from their attachment figure upon reunion and also tend to independently and self-reliantly dissipate their negative emotions without reliance on or help from their attachment figure. Attachment figures of anxious-avoidant children usually respond to the children in a cold and rejecting manner and are more likely to be emotionally or physically abusive. Anxious-ambivalent children typically have an attachment figure whose caregiving has been inconsistent with regards to quality, availability, and responsiveness. These children are more likely to have experienced neglect. They inconsistently and conflictedly attempt to derive comfort and support from their attachment figure. This is often characterized by an intermingling of clinginess and outbursts of anger (Simpson & Belsky, 2016). The fourth category, disorganized attachment, can be seen as a
combination of the three other attachment styles, with no observable clear coping strategy for stressful situations, which results in a temporary breakdown of the child’s behavioral strategies when attempting to cope with stress. These children have likely had inconsistent caregiving and are therefore unsure if they should trust, avoid, or become anxious with regards to their attachment figure (Quas & Fivush, 2009).

Adult attachment styles are also characterized by avoidance and anxiety, which are both related to comfort or discomfort with closeness and intimacy. Attachment anxiety for adults involves a preoccupation with the availability or responsiveness of others to whom one is attached. In adulthood, the primary attachment figure is typically one’s romantic partner (Quas & Fivush, 2009).

2.3.2. Separation from an Attachment Figure

Typically, separation from an attachment figure triggers an attachment response comprised of three phases. It is important to note that these phases are not rigid and an individual does not need to pass through one phase to get to another. The phases are not mutually exclusive, they can, and often do, overlap and individuals may oscillate back and forth between the phases (Fraley & Shaver, 2016). The first phase, the protest phase, is characterized by a forceful reaction including a variety of attachment behaviors, such as crying, which aim to get the attachment figure to return. The second phase is despair. During this phase, anxiety, anger, and denial are replaced with sadness and hopelessness. This is the natural result of the failure to bring back the attachment figure during the protest phase. Bowlby called the third phase detachment, which he considered to be the apparent recovery and gradual renewal of interest in social relationships and other activities, and a defensive suppression of attachment responses which have repeatedly failed (Fraley & Shaver, 2016). Detachment has been reframed by modern attachment theorists as reorganization, where the individual is not defensively trying to suppress their attachment responses, but is
instead trying to reorganize their representation of themselves and others, including the lost attachment figure. This reorganization process involves finding ways to integrate the attachment figure’s legacy, memory, and continued psychological presence into one’s identity, plans, and life (Fraley & Shaver, 2016). The reorganization phase is essentially an adaptation to a new reality without the physical presence of the attachment figure. Interestingly, this separation process is only observed in parent-child relationships and with romantic partner relationships, which is evidence that adults use their romantic partner to regulate their own internal physiological state (Zeifman & Hazan, 2016).

When separation becomes permanent, as in the case of death, the protest phase for children and adults can be marked by enduring preoccupation with the deceased and intense yearning. Once the bereaved adult or child realizes that the separation is permanent and that the deceased will not return, they will likely experience psychological or physiological symptoms such as sleeping and eating disturbances, social withdrawal, loneliness, and dysphoria (Fraley & Shaver, 2016).

2.3.3. Attachment and Grief

Bowlby believed that being able to develop healthy adaptive grief reactions depends on one’s attachment style and research has shown that attachment style may predict bereavement outcome (Quas & Fivush, 2009). Securely attached individuals have been found to adapt to the death of an attachment figure with the fewest complications, whereas insecurely attached adults may be predisposed to psychological difficulties, such as depression or complicated grief, following the loss of a spouse (Neimeyer et al., 2002; van Doorn, Kasl, Beery, Jacobs, & Prigerson, 1998; Waskowic & Chartier, 2003). Insecurely attached individuals are more likely to be left with feelings of anger, guilt, or resentment, all of which would need to be resolved before the
individual can process their grief and adapt to their loss (Waskowic & Chartier, 2003). The people most at risk of developing prolonged grief are those whose attachment style is characterized as insecure, dependent, anxious, or fearful (Fraley & Shaver, 2016). This is in line with Bowlby’s idea that individuals experiencing complicated grief have organized their attachment behavior around the belief that their attachment figure will not be consistently accessible or dependable (Fraley & Shaver, 2016) and may be due to an insecure internal working model which increases the likelihood that the individual would perceive the death of a primary attachment figure as a threat to their safety and security (Neimeyer et al., 2002). There is little research on children’s attachment style and grief, but the results cited above may indicate that insecurely attached children are at greater risk of developing physical or psychological symptoms, such as prolonged grief, following the death of a parent.

2.3.4. Attachment and Communication

Attachment theorists have argued that open, coherent, and emotionally regulated co-constructed dialogues are of importance because they are one of the prime arenas in which parents and children can form and maintain narratives about distressing experiences. Due to their trust in the responsiveness of their parents, secure children should feel more comfortable and capable of openly discussing these types of stressful events with parents, including asking questions and being willing to openly express their fears and concerns to them. In contrast, insecure relationships are characterized by limited sharing, particularly with regards to emotions, and especially negative emotions (Quas & Fivush, 2009). Insecurely attached individuals are often uncomfortable with emotional issues, which may add to a lack of coherence in parent-child communication regarding stressful situations (Bretherton, 1990; Quas & Fivush, 2009). Furthermore, when parent-child dialogues reinforce a psychologically secure base, they can contribute to children’s emotional and behavioral
regulation. However, if they reinforce an insecure base, they are likely to be associated with emotional and behavioral dysregulation (Quas & Fivush, 2009).

2.4. Family Systems Theory

While attachment theory mainly highlights the importance of the parent-child attachment for coping with grief and communicating effectively, it is important to note that parent-child relationships do not exist in a vacuum. In order to understand an individual’s behavior, you must understand their environment as well (Bowlby, 1975; Mallon, 2008). Parents and children interact with other family members, their wider social network, and society. There are several types of systems theory, but the general idea is that families or individuals are part of systems and subsystems which are interdependent on one another, where a change in one system will cause change in the other interrelated systems.

The family is a system comprised of subsystems. Each individual could be considered its own subsystem, or subsystems can be divided by generation, i.e., siblings, parents, grandparents, and the family’s wider social network (Figure 1) (Lamberti & Detmer, 1993). When a change occurs in one of these subsystems or in the system as a whole, this initial change is followed by a compensatory change or sequence of changes in other parts of the system or other subsystems. These compensatory changes are an attempt to account for or balance out the initial change (Bowen, 1966).
Figure 1. Overview of Family Systems Theory.

Bowen (1982) examined grieving families from the logical perspective of how each individual affects and is affected by mourning within the family system. Bowen noticed that grieving patterns are often passed down through generations. Furthermore, families tend to act in dyadic patterns and shift or spread anxiety and stress to a third person, which is often referred to as triangulation. When a family member dies, the number of dyads and triangles diminishes, which may cause family members to shift alliances or to be left feeling as if no one is on their side (Kerr & Bowen, 1988).

Differentiation refers to an individual's ability to utilize cognitive and emotional skills. Families can exhibit high or low levels of differentiation and be classified as either open or closed. Open families exhibit a high level of differentiation, meaning that family members are able and willing to openly communicate their thoughts and feelings with each other. In bereaved families, a high level of differentiation is apparent when each family member is allowed to express their grief in their own way, and family members are accepting of each other's unique expressions of grief. Open families experience less disruption and
more effective coping than closed families, where freedom of expression is not allowed (Kerr & Bowen, 1988).

Bowen (1966) developed his version of family systems theory based on his own clinical experience working with individuals and families. This theory in turn helped to inform new techniques, treatment methods, and theoretical orientations in family therapy. Bowen saw family therapy as a forum for acquiring new ways to conceptualize family phenomena and discussion of family experiences. He believed that family therapy required the entire family, usually parents and children, to be seen together by a therapist with the goal being for the family to learn to verbalize and communicate their thoughts and feelings to each other. The therapist’s job was essentially to facilitate this process. Bowen observed that even slight improvements in communication could produce dramatic shifts in how the family felt (Bowen, 1966).

2.5. Ecological Systems Theory

Ecological systems theory is similar to family systems theory, but instead describes the relationship between families, institutions, and the welfare state. Like in family systems theory, the systems are interdependent on one another. If an intervention is conducted or routines are changed in one system, this will affect the other systems (Bronfenbrenner, 1977). One example of this is that laws and policies – which comprise the macrosystem – affect how resources are allocated, which services are provided in the welfare state and by which institutions, which inevitably affects what types of support families can receive from different institutions (Bronfenbrenner & Morris, 2007). As the family members struggle with their own grief, attempt to maintain or strengthen attachment bonds, and cope with changes to family life, they must also find a way to navigate these ecological systems which should be providing supportive resources to the family (Figure 2).
2.6. Meaning Making

Robert Neimeyer’s (2001a, 2001b, 2002) theory of meaning making presumes that individuals are shaped and sustained by their attachments to others and that these attachments help to anchor the meaning in an individual’s life. The loss of an attachment figure challenges the individual’s assumptions about who they are and challenges an individual’s sense of narrative coherence and sense of identity. To cope with this, the bereaved individual must reorganize and rewrite their life story in a coherent way that bridges the past and the future (Neimeyer, 2001a). This is similar to the concept of reorganization in attachment theory (Fraley & Shaver, 2016). To do this, an individual constructs their own unique response to grief by distilling the meaning of the loss from their perspective, from their family’s perspective, and from a community and cultural perspective, which in turn influences how that individual copes with grief (Neimeyer, 2001a). Through narratives or stories, the self is constructed and reconstructed in relation to an individual’s social world, from which they receive validation. From this theoretical perspective, meaning is comprised of...
cognitions, interpretations, self-statements, language, cultural practices, spiritual traditions, and interpersonal conversations (Neimeyer et al., 2002).

### 2.7. Family Meaning Making

Nadeau (2001) points out that a family, as a family system, searches for meaning following the death of a family member in a similar way that individuals do. Most of the meaning making process happens in family relationships through conversation or other types of communication. Family meaning making occurs at all system levels and within all subsystems. Some meanings are agreed upon right after the death and others develop over time. The family’s collective willingness and ability to share, how often they talk, family rituals, tolerance of differences, and the way the person died may all enhance family meaning making. On the other hand, family secrets, fragile family ties, divergent beliefs, and family rules which prohibit sharing tend to inhibit family meaning making (Nadeau, 2001). From a family systems perspective, it could be assumed that open families would be more likely to successfully engage in the family meaning making process than closed families (Kerr & Bowen, 1988).

Understanding the ways in which families find meaning in their grief and bereavement is crucial to the development of successful support interventions for bereaved families, and family communication seems to be the main way family members make sense of their loss (Nadeau, 2001). By talking as a family, bereaved family members seem to develop a shared sense of what the death meant (Nadeau, 2001). Several communication strategies are used in family meaning making, including storytelling, characterization, and family speak. Storytelling is the most common strategy families use in the meaning making process. Meaning and important family themes are embedded in the stories family members tell about the deceased, about themselves, and about each other. Characterization occurs when family members describe who the deceased...
family member was as a person and helps to make sense of the person’s death by making sense of their life. Family speak is the use of ordinary conversation including agreeing, disagreeing, interrupting each other, echoing each other’s meaning, elaborating on something someone else said, and finishing each other’s sentences, all of which help to create a shared sense of meaning (Nadeau, 2001).
3. Background

3.1. Families in the Swedish Welfare State

The Swedish welfare state was built up in the 20th century with a strong focus on children. By the late 1800s, the Swedish state had already begun to realize that the children needed to be protected and looked after, as not all parents had the necessary skills or conditions to do so. At that time, juvenile delinquency, infant mortality, malnourishment, poor hygiene, childhood illnesses, and alcoholism had increased and the population size was dwindling, signaling the need for someone to respond and help the children. The assumption was that if children had good living conditions they would grow up to become caring workers and responsible citizens. Because of this, the state began working to create layers and rules that were focused on the rights and autonomy of children and took on the responsibility to protect all children in Sweden. As a result, an alliance started to form between the children and the state and children started to be considered as both a collective resource and autonomous individuals, rather than their parents’ property (Berggren & Trägårdh, 2015).

The purpose of the state taking on these obligations was to increase equality and ensure that all children, regardless of social class, had equal conditions and therefore equal opportunities. The idea was to ensure that all children could be in day care or school, where the state would take responsibility for teaching the child how to be a good citizen (Sandin & Halldén, 2003). By the 1930s, children gained access to education through public schools, which the state also took responsibility for (Berggren & Trägårdh, 2015). Around the same time, the value of taking the child’s perspective or the concept of acting in “the best interests of the child” emerged. Today, various authorities and agencies operating in the welfare state use the concept of “the best interests of the child” for different purposes and in different contexts. This is meant to create a
common starting point for all authorities and agencies in Swedish society, with the aim of everything being child-centered (Sandin & Halldén, 2003).

The more democracy evolved during the shift towards the welfare state in the 1930s, the more the family unit was seen as competing with the state for each citizen’s loyalty. Consequently, the family was seen as decidedly undemocratic due to its hierarchical nature characterized by unequal power structures and unequal decision making. At the time, the Social Democrats had the goal of building a society full of enlightened, emancipated, autonomous individuals. From the state’s perspective, the family was essentially just another outdated hierarchical institution governed by patriarchal power structures. A main theme in Swedish politics and especially for the Social Democrats therefore became the emancipation of children – and, later, women – from the constraints of the family, with the aim of creating a more equal and just society (Berggren & Trägårdh, 2015).

During the 1950s, pensions increased, stipends were given to all families who had children regardless of financial need, and an insurance system was introduced making it possible for everyone to benefit from a minimum standard of security (Berggren & Trägårdh, 2015). Insurance, pensions, and financial stipends still exist today in various forms. These include stipends and insurance to assist with a family’s mortgage or rent when one’s partner dies, paid leave from work to care for a sick family member, and sickness or disability pay for bereaved individuals (Efterlevandeguiden, 2019), all of which may help to make the family’s adjustment following a parent’s death less stressful, at least financially.

The insurance system established in the 1950s also set the foundation for the current Swedish health care system, which is comprised of 21 regional bodies responsible for primary and specialized, inpatient and outpatient, somatic and psychiatric care. These regions all operate autonomously, through state-funded hospitals and clinics, as well as private hospitals and clinics, which are
typically funded indirectly by the state through various types of reimbursement plans with different types or levels of services of care being incentivized depending on the specific reimbursement plan (Lindgren, 2019).

Due to the high level of trust in the Swedish welfare state and the strong emphasis on individuals remaining autonomous and not having to rely on others for anything, volunteer and non-profit organizations are not as common as in other countries, such as the United States. In the United States, non-profit organizations, religious groups, and charities are often expected to meet the needs of the population by providing schools, day care centers, crisis management, and psychosocial support for underserved populations (Berggren & Trägårdh, 2015). In Sweden, people in need of support, such as parentally bereaved families, often fall through the cracks, since the resources offered by the welfare state, e.g., psychological health care or social services, seldom meet the needs of the population.

At a national level, specialized psychiatric care clinics for children and adolescents have had long wait lists for years, promoting the creation of pediatric primary care clinics for children and adolescents who are experiencing mild to moderate psychological health problems (The Swedish Association of Local Authorities and Regions). Many parentally bereaved children and adolescents likely fall into this category. An evaluation of these primary care clinics’ performance in 2016 concluded that they were still prioritizing children with moderate to severe levels of symptomology, indicating that children with mild to moderate concerns and those in need of preventive care were likely still not getting the help they needed (Siren, Wicks, Lindberg, & Dalman, 2018).

Schools offer another option for preventive care. However, there are no guidelines on what level of education is adequate for school counselors in Sweden; most have a three-year undergraduate degree in social work with little or no formal training in working with grief. They are allowed to hold supportive talks with students and give students advice primarily regarding the student’s
academic success, with referrals being sent to primary care, specialized care, or social services as needed (Hedwall & Larsson, 2016).

In the case of palliative care, children tend to become more involved as relatives and are therefore more likely to have access to bereavement support than in other health care settings (Breen, Aoun, O’Connor, & Rumbold, 2014; Payne, 2010a; Radbruch & Payne, 2009). The National Board of Health and Welfare has presented national guidelines for palliative care in Sweden as well as guidelines for providing support to parentally bereaved children and their families (National Board of Health and Welfare, 2016b, 2017). Despite these recommendations, bereavement support for children and adolescents is underprovided. This is primarily due to the organizational structure of the Swedish health care system, as there are no clear divisions of responsibilities and no clear routines regarding the implementation of bereavement support interventions. Furthermore, a survey from three counties in Sweden found that support interventions for children who have lost a parent are not readily available, despite the fact that approximately half of bereaved children and adolescents felt that support was needed (Bergh Johannesson et al., 2014). This is also in stark contrast to the United States, where counseling and psychotherapy are frequently offered as the solution to a wide range of grief reactions (Neimeyer et al., 2002). One reason for the lack of organized and structured resources for bereaved families is likely the decentralization and privatization of the Swedish welfare society, which has been ongoing since the recession in the 1990s. This decentralization and privatization has offered citizens more freedom of choice, especially with regards to health care providers, but has also made it more difficult to hold the state responsible for the quality of services offered (Berggren & Trägårdh, 2015).

In comparison, both Norway and Denmark have national centers focused on grief (The Danish National Center for Grief, 2019; Centre for Crisis Psychology, 2019a). In Norway, the Centre for Crisis Psychology is a national
competence center that conducts research and disseminates knowledge related to grief and crisis. They hold courses for the general public as well as for professionals working in education, health care, and emergency services. Grief counseling and therapy are offered through the Clinic for Crisis Psychology, which was founded in 1988 (Centre for Crisis Psychology, 2019c). Norway also has a centralized website where bereaved individuals can search for a grief support group in their area (Center for Crisis Psychology, 2019b). These support groups are run by public and private organizations. The Danish National Center for Grief was founded in 2017 in order to provide specialized psychological health care to grieving individuals ages 28 years or younger and their families. The center conducts research, disseminates knowledge, and provides professional training to health care providers. This training is focused on how to respond to and support bereaved individuals and families and helping professionals to recognize normal and complicated grief. There are three physical counseling locations in Denmark, but counseling is also provided via telephone and internet chat, primarily by adolescent and young adult volunteers who have personal experience with grief and bereavement. Unlike Norway and Denmark, Sweden does not have centralized online resources with information on where individuals and families can turn for help. In some parts of Sweden, the Swedish Church and other non-profit organizations do offer bereavement support, but these efforts are often poorly structured, have strict rules regarding who can participate (child age, time since death, etc.) and are typically not evidence-based bereavement support interventions (Hansson, 2012).

3.2. Palliative Care

In 1957, Cicely Saunders was writing about the importance of having specialized homes for dying patients with specialist practitioners who knew how to treat pain, mental distress, fear, and resentment, along with the somatic complications associated with dying. She was also discussing the notion of
telling patients and their families about the patient’s diagnosis and prognosis, which was a controversial idea at the time (Clark, 1998). Saunders’ hospice strategy, based on the combination of social, spiritual, and professional care, continued to gain popularity. This strategy acknowledges the history of religious organizations caring for the sick and dying, while prioritizing modern medical and nursing practices (Clark, 1998).

St. Christopher’s Hospice was opened by Cicely Saunders in 1967, which sparked a global hospice movement (Clark, 1998) with the type of care provided in hospice centers eventually being referred to as palliative care. Over time, palliative care was established as a specific medical and nursing specialization. The World Health Organization defines palliative care as an approach aimed at improving the quality of life of patients and their family members when facing life-threatening illness. This is meant to be accomplished through the prevention and relief of physical, emotional, and spiritual suffering by means of early identification, assessment, and treatment – including psychosocial and spiritual support for the patient’s family – both before and after the patient’s death (World Health Organization, 2002). Within the field of palliative care, there is an agreement that family members should be supported by helping to prepare them for the loss of the patient before the patient dies and by providing bereavement support afterwards, with bereavement support being considered a core component of palliative care (Radbruch & Payne, 2009, 2010b).

In Sweden, palliative care is provided by the welfare state at hospitals, hospice centers, and by specialized home care teams. Palliative care uses an interdisciplinary approach where doctors, nurses, social workers, psychologists, physical therapists, nutritionists, and volunteers all work together to meet the needs of each individual patient, regardless of where the patient is being cared for. Emphasis is also placed on collaboration between staff, patients, and families, where patients and families are actively involved in making health care decisions (Radbruch & Payne, 2009). General palliative care is provided together
with curative treatment to reduce the patient’s physical, psychological, and spiritual symptoms of pain and discomfort, while keeping the family informed of the patient’s prognosis. Specialist palliative care, on the other hand, is provided by specialized palliative care clinics where palliative care is the main form of care being provided. These may include hospices, inpatient palliative care wards, or specialized home care teams. Specialized palliative care also deals with more complex patient and family needs and bereavement support (Radbruch & Payne, 2009).

3.2.1. The Family in Palliative Care

Palliative care settings may serve a protective role by reinforcing the emotional wellbeing of family members. One reason for this may be that involvement in a palliative care setting often induces anticipatory grief processes in both patients and their family members (Fasse et al., 2014). Helping people prepare for the death of a family member due to illness likely increases their resiliency following the death of a family member, whereas a lack of preparation for a family member’s death has been associated with prolonged grief. Furthermore, psychological and somatic symptoms associated with bereavement may be reduced or even prevented by educating people about causes, risks, and solutions for their symptomology (Kellehear, 2015). Similarly, some studies have found that low levels of preparedness before a spouse’s death may increase bereavement complications (Hauksdóttir, Steineck, Fürst, & Valdimarsdóttir, 2010; Rando, 2000). On the other hand, Higginson et al. (2003) and Ringdal, Jordhøy, Ringdal, and Kaasa (2001) found that palliative care offered no additional benefits to bereaved family members when using a universal approach to bereavement support, meaning that they offered the same support services to all families regardless of need or risk of developing complications. Research has shown that professional bereavement counseling or therapy is usually not effective or beneficial when offered using a universal approach and
that counseling and therapy are most effective when sought out by the individual or when selectively offered to those at high risk of developing complications as a result of their bereavement (Aoun, Breen, O’Connor, Rumbold, & Nordstrom, 2012; Currier, Holland, & Neimeyer, 2007; Jordan & Neimeyer, 2003; Neimeyer & Currier, 2009; Schut, 2010; Stroebe & Schut, 2010; van der Houwen et al., 2010). Routine assessment of family resilience and functioning may help palliative care teams target bereavement support interventions to the families most in need (Kissane, Lichtenthal, & Zaider, 2007).

3.2.2. Bereavement Support for the Family

Previous studies have shown that bereaved family members may be in need of psychological support, including emotional, social, and spiritual support (Payne, 2010b). Bereavement support interventions for families often include group interventions, family interventions, parental guidance, and camp activities for children and families (Bergman, Axberg, & Hanson, 2017), as well as play therapy, expressive arts therapy, family therapy, and cognitive behavioral therapy (Chen & Panebianco, 2018). Most bereavement support interventions are comprised of psychoeducation and family-based components. Support interventions have been found to be effective at preventing the development of more severe psychological problems when targeting the child, surviving parent, or both, with evidence that even relatively brief support interventions may be beneficial (Bergman et al., 2017). Several studies evaluating interventions for preschool-aged children found that the children exhibited fewer symptoms following the intervention, but the differences were not statistically significant. However, qualitative data from these studies provided a narrative, usually from the parent’s perspective, supporting the effectiveness of the interventions, including helping young children to understand the concept of death, helping
children to express their grief, and normalizing grief reactions (Chen & Panebianco, 2018).

Perhaps the most thoroughly studied intervention for parentally bereaved families is the group-based Family Bereavement Program (FBP) (Bergman et al., 2017; Sandler, Gersten, Reynolds, Kallgren, & Ramirez, 1988; Sandler et al., 1992). In the FBP, parent and child groups meet separately for 12 two-hour sessions to cover several topics including improving relationship quality, positive coping strategies, emotional expression, and grief (Ayers et al., 2014). The FBP uses collaborative and active learning strategies such as modeling behavior, practicing new skills, and role-playing. Furthermore, by teaching parents and children effective skills for listening and expressing emotions, which are reviewed and practiced when negotiating and planning positive family activities, emotional support may be promoted (Sandler et al., 1988).

Randomized controlled trials of the FBP resulted in improved parenting skills, improved skills for coping with stress, and improved mental health for parents and children, as well as higher self-esteem and improved self-reported academic performance for younger children (Ayers et al., 2014; Sandler, Ayers, & Romer, 2002; Sandler et al., 2003; Sandler et al., 1992). At a fifteen-year follow-up, bereaved young adults who had participated in the FBP reported significantly less use of mental health services and psychiatric medication and fewer internalizing and externalizing problems than the control group. Similarly, bereaved parents who had participated in the intervention had significantly lower rates of alcoholism and lower use of support groups than parents who had been in the control group (Sandler et al., 2018).
3.3. Psychological Health Following the Death of a Parent

Common psychological health problems experienced by parentally bereaved children include internalizing problems – such as depression, anxiety, emotional problems, or difficulty forming relationships with peers – as well as externalizing problems – such as aggression, delinquency, hyperactivity, and conduct problems. Parentally bereaved children are also at risk of developing symptoms of prolonged grief following their parent’s death (Ayers et al., 2014; Dowdney, 2000; Spuij, Dekovic, & Boelen, 2015; Stikkelbroek, Bodden, Reitz, Vollebergh, & van Baar, 2016). Similarly, increased self-harm behavior and difficulty maintaining relationships in adulthood have been identified as common consequences of parental death during childhood (Bylund Grenklo et al., 2014; Høeg et al., 2018).

Surviving parents may develop similar psychological health problems (Shear, 2012; Worden & Silverman, 1993). Previous research has shown that a child’s response to a parent’s death is often mediated by how their surviving parent responds to the loss (Green & Connolly, 2009), as the parent’s own grief reaction will usually affect their ability to parent and communicate with the child (Shapiro et al., 2014). One of the strongest predictors of young children’s coping ability following parental death is if their surviving parent develops depression (Bugge, Darbyshire, Røkholt, Haugstvedt, & Helseth, 2014; Wolchik et al., 2006). This may be because parents with depression or a history of depression often have a more detached and negative parenting style to begin with, which can lead to the child expressing psychological symptoms of their own (Shapiro et al., 2014).
3.3.1. Internalizing and Externalizing Problems

Internalizing problems, such as social withdrawal, inhibition, depression, or anxiety, are thought to be a result of excessive control over one’s thoughts, behaviors, and emotions. Internalizing problems typically have an immediate impact on the individual child, such as limiting their social experiences, which in turn creates obstacles for the child’s psychosocial development. Externalizing problems, on the other hand, are thought to stem from low levels of control over one’s thoughts, behaviors, and emotions, which are then expressed through aggressive, impulsive, antisocial, and challenging behaviors which tend to immediately impact other people (Neves Nunes, Faraco, Vieira, & Rubin, 2013). Internalizing problems in childhood or adolescence have been associated with future disability pension due to a diagnosis of depression and/or anxiety. Similarly, externalizing problems, and especially rule-breaking behavior, during childhood or adolescence, have been associated with an increased risk of sickness absence in young adulthood. Furthermore, the development of externalizing problems in childhood or adolescence increases the risk of internalizing problems as well as physical health problems in adulthood (Narusyte et al., 2017).

Another main factor often attributed to the development of internalizing and externalizing problems is the quality of the parent-child relationship, with specific parenting behaviors – such as rejection and control – predicting both types of problems. Children whose parent is controlling, very affectionate, and paradoxically unresponsive to the child’s actual needs seem to be at highest risk of becoming socially withdrawn, whereas parental rejection best predicts the development of anxiety and depression. Low levels of parental control, such as a lack of boundaries and discipline, have been found to be a predictor of the development of externalizing problems (Neves Nunes et al., 2013).
3.3.2. Prolonged Grief

Symptoms of prolonged grief, a type of complicated grief, include a sense of disbelief that the death happened, feelings of anger, guilt, or bitterness, prolonged intense yearning, intense painful emotions, rumination, catastrophizing, and avoidance of reminders of the loss (Prigerson, Vanderwerker, & Maciejewski, 2008; Shear, 2012; Shear & Shair, 2005; Spuij et al., 2015). In children and adolescents, prolonged grief has been associated with increased suicidal ideation and impairments in health and quality of life, including greater functional impairment within the first year following a parent’s death and at three-year follow-up (Melhem et al., 2004; Melhem, Moritz, Walker, Shear, & Brent, 2007; Melhem et al., 2011). A prior personal history of depression may help to predict the development of prolonged grief. Additionally, the combination of prolonged grief in the surviving parent and in the child, was found to be particularly influential in predicting depression in children up to three years after the death of a parent (Melhem et al., 2011).

3.4. Communication

Family communication has been shown to be important with regards to attachment theory and family meaning making. According to Miller (1966), communication includes all aspects of human behavior through which an individual consciously attempts to transmit a message to someone else with the intention of affecting the listener’s behavioral response. Communication can also help to develop and alter a person’s sense of self and the world around them (Manusov, 2016). Verbal communication, such as speaking, is often considered to be an intentional behavior, as people typically think about what they are going to say and have an intended purpose with speaking, such as sharing information or getting another person’s attention. Non-verbal communication, on the other hand, is believed to be responsible for the emotional meaning attributed to a message and is comprised of body language,
such as facial expressions, posture and gestures, physical appearance, and tone of voice. Non-verbal communication also includes one’s ability to express or decode emotions and motivation (Manusov, 2016; Stacks, Hickson, Deyo, & Walt, 2011).

3.4.1. Family Communication

Modern families tend to be more democratic, which often leads to more active egalitarian communication between parents and children, as children are increasingly considered autonomous individuals with an equal right to express their thoughts and feelings (Haselhoff, Faupel, & Holzmüller, 2014). In most families, both mothers and fathers take time to talk to their children in order to immerse themselves in their children’s experiences, while at the same time acknowledging their children’s unique perspectives and sentiments. When this democratization is combined with an emphasis on the importance of authenticity, reciprocal voicing of one’s inner states tends to become prioritized and family members are more likely to openly share their feelings with each other, which leads to genuine family connectedness (Ochs & Kremer-Sadlik, 2015).

3.4.1.1. Family Communication and Psychological Health Following the Death of a Parent

How parents and children communicate following the death of a parent may significantly affect surviving children’s well-being and family functioning, but offering support and communicating effectively may be difficult for bereaved parents as they deal with their own grief. Previous research shows that the surviving parent’s ability to communicate with their child is often affected by their own grief reaction, which in turn may affect the child’s ability to cope with the loss (Field et al., 2014). In general, mothers who develop moderate to severe depression following a significant loss have been found to use more negative and detached communication patterns, which can lead to the development of
psychological symptoms in children. In contrast, parents who report mild to moderate symptoms of depression, which one might expect to be present in a normal and adaptive grieving process, more frequently used effective communication strategies with their child than parents who reported no symptoms of depression following the death of their spouse (Shapiro et al., 2014). Parents who are, consciously or unconsciously, suppressing or not expressing negative affect during bereavement are not modeling appropriate emotional expression or providing a context in which their children can express grief and other loss-related emotions. This in turn disrupts the child’s facilitation of grief and mourning (Shapiro et al., 2014). Conversely, research has shown that children who speak with their surviving parent about the parent’s death tend to have better psychological outcomes than those who do not talk about it.
4. Aims

The overall aim of this thesis was to explore and describe psychological health, grief and family communication among bereaved children and surviving parents in order to develop and evaluate a supportive family intervention which may prevent the development of psychological health problems in parentally bereaved children.

4.1. Specific aims

- Explore and describe both child and parent experiences of family communication in the first 14 months following a parent’s death to cancer (Study I).
- Examine the relationship between family communication and specific aspects of psychological health of children and adolescents, including emotional problems, conduct problems, prosocial behavior, hyperactivity, peer problems, and prolonged grief following a parent’s death from cancer using parent-proxy and adolescent self-reports (Study II).
- Describe the adaptation of the evidence-based Family Bereavement Program to a Swedish context (Study III).
- Evaluate intervention fidelity and explore family members’ experiences and perceived outcomes after participating in the Grief and Communication Family Support Intervention (Study IV).
5. Methods

5.1. Design

This research project used a mixed-method multiphase design (Creswell & Plano Clark, 2011). Studies I and II used a sequential exploratory design with qualitative data being collected first (Study I) to inform the content of the questionnaire which was used in Study II. The results from Studies I and II helped to identify family-related factors which were important to parentally bereaved families. These family-related factors were compared with empirical evidence from previous research and aided in the development of the intervention manual (Study III). Results from Study III further influenced the design of Study IV, which used a Concurrent Triangulation Design. In this design, qualitative and quantitative data were collected concurrently at one-month follow-up. The data were analyzed separately and then compared and combined to confirm, cross-validate, and corroborate findings (Creswell & Plano Clark, 2011) (Figure 3; Table 1). By using this design, the research project resulted in cumulative knowledge, meaning that the results from each study have successively built upon the results from the preceding studies.

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<tr>
<th>Interview</th>
<th>Questionnaire</th>
<th>Intervention</th>
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<tr>
<td>Study I: Explore family</td>
<td>Study II: Explore associations between</td>
<td>Study III: Adapt and test intervention</td>
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<td>Build parent-proxy and</td>
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<td>adolescent questionnaires</td>
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Figure 3. Overview of studies.
Table 1. Overview of the four studies included in this project.

<table>
<thead>
<tr>
<th>Study</th>
<th>Aim</th>
<th>Participants</th>
<th>Data collection</th>
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| I     | Explore and describe child and parent experiences of family communication | Parents n = 4  
  Children n = 4 (ages 6–18 years) | Interviews and repeated interviews | Inductive content analysis |
| II    | Examine the relationship between family communication and psychological health of children and adolescents | Parents n = 39  
  Children n = 55  
  Adolescents n = 23 | Study-specific questionnaire | Descriptive statistics  
  Spearman rho correlation |
| III   | Describe the adaptation of the Family Bereavement Program to a Swedish context | Parents n = 2  
  Children n = 3 | Adherence checklist and audio recordings  
  Participant feedback | Description of development process and participant feedback |
| IV    | Evaluate fidelity and explore family members’ experiences and perceived outcomes after the Grief and Communication Family Support Intervention | Parents n = 10  
  Children n = 14 | Baseline and follow-up questionnaires  
  Follow-up interviews  
  Adherence checklist and audio recordings | Inductive qualitative analysis  
  Assessment of fidelity |
5.2. Participants and Procedures

A total of 44 parents and 62 children ages 3 years and older participated in the four studies included in this research project. These families had lost a parent to cancer sometime in the four years prior to participation and all lived in Stockholm County, Sweden. This research project was approved by the Regional Ethics Committee DRN 2016/1192-31/1. Informed consent was collected from all participating children after the family received written and verbal information about the study and prior to starting each of the four studies. Participants were informed that they could stop participation at any time. In each of the studies, there were several families that called to decline participation, thanking me for doing valuable research and explaining that at that time, their family was not emotionally able to participate. Some reasons given were that the family had “just gotten through this and didn’t want to open old wounds” or that they were “trying to focus as much as possible on returning to normal life.” These responses may have had to do with the range in time since loss of 1–3 years. Families who had lost a parent one-year prior may not have been emotionally ready, whereas families who had lost a parent three years prior may have found a way to cope and move on and therefore not have wanted to focus on their loss again.

5.2.1. Study I

Participants were recruited from two palliative care centers with the help of health care personnel, including nurses and counselors. Inclusion criteria were families with children ages three years and older who had lost a parent to cancer within the past three years. Nineteen families meeting the inclusion criteria were identified. All the families who wished to participate did.

A total of eight interviews were conducted with four parents, one 18-year-old son, and three daughters ages six, eight, and nine years of age. Parents
were sent an informational letter via post, which was followed up one week later with a phone call to explain more about the study and answer any questions the parent might have. Parents were excited to participate, but unsure about allowing their children to participate. I decided to hold interviews with the parents in the hopes that they would later allow me to interview their children. I met with each of the four parents for an initial interview regarding their experiences of having a partner die of cancer and asked about their perception of their children’s experiences as well. After these initial interviews, a preliminary analysis was conducted which identified several areas of focus, with family communication being the most interesting and relevant to the development of the intervention. I then contacted the parents again by telephone and asked if they would like to participate in a second interview, possibly with their children, so that I could learn more about how members of their family communicate with each other. At this point, repeated interviews were conducted with all parents, and three out of four agreed to let their children participate in the interviews.

The eight interviews were conducted, transcribed verbatim, and analyzed using qualitative content analysis (Elo & Kyngäs, 2008) to explore and describe child and parent experiences of family communication in the first 14 months following a parent’s death to cancer. This analysis was also discussed during a department seminar to strengthen its validity. Later, the research group met and discussed the analysis process, and came to a consensus regarding the results. A secondary aim of the interviews was to aid in the development of the study-specific questionnaire which was used in Study II.

5.2.2. Study II

Individuals who died of cancer between 2013 and 2015 and were between the ages of 25 and 65 years at the time of death were identified through the Swedish National Causes of Death Register. Each deceased person was
linked to offspring using the Multi-Generational Register at Statistics Sweden to identify if he or she was the parent of a child or children between the ages of 1 and 18 years at the time of death. The participants were the deceased’s surviving partner and children. Questionnaires were collected for 39 parents, 55 children and 23 adolescents.

The parent, adolescent, and child (parent proxy) questionnaires were developed using Charlton’s (2000) recommendations for constructing a study-specific questionnaire. Together with my three advisors, I defined the research question and conducted a literature search to identify key concepts and themes as well as validated instruments which might be acceptable for inclusion in the questionnaire. This was an important step to discover what was already known about the experiences of parentally bereaved families and to identify areas where less information was known or that had not been explored previously. In discussion with my three advisors, who had previously used this methodology and who are well experienced in the field of bereavement, validated instruments were chosen and recurring themes were turned into hypothetical constructs which eventually became potential questions. Questions from nationwide surveys conducted previously by the research group were also used (Eilegard, Steineck, Nyberg, & Kreicbergs, 2013; Grenklo et al., 2013; Kreicbergs et al., 2005).

A preliminary version of each questionnaire was distributed to colleagues for feedback regarding the language used and the relevance of each question, which helped to ensure content validity (Charlton, 2000). After this, a pilot of the questionnaire study was conducted, where the families who participated in the interviews (Study I) were contacted again and asked if they would help with face-to-face validation of the questionnaires. Some parents asked to receive the questionnaires via post or to pick them up from the research center to take home and leave written comments and feedback regarding the questions. Others, including the 18-year-old son, came to the research center to discuss
each question included in the adolescent questionnaire. These participants gave suggestions for rewording questions, adding more open questions, and adding more response alternatives. They also went through each question with a member of the research group to check for understanding and ensure that each question was appropriate and not too emotionally charged.

Once the questionnaires were finished and all changes requested during the pilot had been made, the questionnaires were digitized to an online format. Eligible families were sent an informational letter in the post which included a link to a website where families could sign up to participate in the study. Once they had signed up, a link to an online questionnaire was sent to their e-mail address.

Participating parents filled in a parent questionnaire about their own experiences as well as a proxy questionnaire for each of their children ages 3–19 years. Adolescents ages 12 years and older were asked to fill in an adolescent self-report questionnaire.

5.2.3. Study III

Two families participated in the first test of the Grief and Communication Family Support Intervention. Family one was comprised of a father who had participated in Study I and his two sons ages 6 and 11 years. Family two was recruited through our research group’s professional network and was comprised of a mother and her 7-year-old son.

During the eight interviews with parentally bereaved families in Study I, participants described that help and support for parentally bereaved children was lacking and stated that more support was wanted and needed. Parents provided information on what types of help and support they had looked for, what was available, and what they had received or wished they had received. The participating families were not interested in meeting other families where a parent had died as they felt it would be too difficult or overwhelming. This
reinforced the decision to create a family-based intervention rather than a group-based intervention.

In order to create this family-based psychosocial intervention for parentally bereaved families, three licensed family therapists were invited to meet with the research group to discuss designing the intervention. Once the therapists agreed they wanted to collaborate on this project, I continued to meet with them approximately once a month for one year, with each meeting being approximately 2–3 hours long. During these meetings, we discussed the design of the intervention, how many sessions should be included, theoretical orientation, inclusion and exclusion criteria, and content of the modules. It was decided after much consideration that a brief intervention consisting of three sessions, each 90 minutes long and conducted as close to one week apart as possible – which is typical for this type of intervention in clinical practice – would be best suited to our population and hopefully more accessible for families with children.

Based on previous literature on interventions for bereaved children and families, and discussion with the creator of the Family Bereavement Program (FBP), Professor Irwin Sandler, we decided that the focus of the intervention should be grief and communication. I received a copy of the FBP treatment manual for both the child program and the parent program from Professor Sandler. With the help of the three family therapists, we adapted several modules from the group-based FBP to fit a family format by combining the parent and child communication modules, which are meant to complement each other in a group format. Based on the discussions during the meetings with the therapists, I would work on writing various elements of the intervention manual, which I would then send to the therapists for feedback. The therapists were instrumental in adapting the FBP manual from an American context to a Swedish one by replacing examples given in the FBP manual with culturally relevant examples and adjusting the language used in the manual to be less direct
and more culturally appropriate. For example, “parents should” was changed to “it could be helpful to try.”

Collaboration with the family therapists and Professor Irwin Sandler during Study III led to successful adaptation of group-based modules from FBP to family-based modules in the intervention. After testing the intervention manual with two families, follow-up phone calls were made to the parents to get feedback on the intervention.

5.2.4. Study IV

Five mothers and five fathers were recruited from Study II to participate in a trial of the Grief and Communication Family Support intervention along with their 14 children. This recruitment was done with the help of the questionnaire in Study II, where the final question in the parent questionnaire asked if the family would be interested in participating in the intervention study. I contacted the families who responded that they would like to participate or would like to receive more information by telephone. There were no inclusion or exclusion criteria with regards to mental or physical illness, having previously sought counseling, therapy, or receiving any other type of psychosocial support. This was an attempt to keep our sample as close to a realistic community population as possible.

Written informed consent was collected at the beginning of the first session, at which time therapists asked each family if they were willing to consent to having their sessions audio-recorded so that the research team could assess for 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. I listened to each recorded session and filled in an
independent adherence checklist which was then compared with the therapist self-report checklist.

Parents were asked to complete one-month follow-up questionnaires for themselves and each of their children. They were also invited to an interview, at 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 seven parents and ten children.

5.3. Data Collection

5.3.1. Interviews

I conducted interviews with bereaved families at the research center or in the family’s home, depending on the family’s wishes. Parents could decide to be interviewed alone or include their children. Adolescents were given the option to participate in a family interview or have their own interview without their parent or siblings present. Interview guides were used for all interviews.

In Study I, interviews were conducted with parents from the four families. Each interview was recorded and lasted 45–90 minutes. The interview guide was comprised of open questions about how the family has been since the loss, how family members felt, family communication, and relationships between family members. Specific questions probed who the children talked to about the deceased parent, what the parent and children thought had been difficult, what they thought had been good and how they were feeling at the time of the interview. Interviews were conducted in the family’s home or at the research center depending on the participants’ preferences.
The first interview helped to build trust with the parents so that they would allow their children to participate in the repeated interviews. During the first interviews, parents were very forthcoming with information regarding their experiences, both positive and negative. Following the preliminary analysis of the first interviews and upon formulation of a more specific research question, families were contacted again. The repeated interviews were conducted 2–5 months after the first interviews, at which time most parents felt comfortable including their child/children in the interview. The purpose of the repeated interviews was to provide a deeper understanding of family members’ experiences of family communication and enabled children and adolescents to have their perspectives heard. These interviews focused primarily on how the surviving family members communicated with each other, both verbally and non-verbally. Questions asked during these interviews were influenced by responses given in the first interviews: for example, asking children to elaborate on anecdotes that their parent had mentioned in the first interview. Young children participated in two of the repeated interviews, both conducted in the respective family’s home with the surviving parent present. Children participated actively and often had their pets with them for support and comfort. The children were able to answer questions with minimal prompting and spontaneously shared toys and drawings which reminded them of their deceased parent. The surviving parents were very careful not to interrupt their children, giving them the opportunity to answer questions without help or input. All questions were modified to be age-appropriate and were followed up with probing questions to elicit more information. One 18-year-old son decided to participate in an interview at the research center without his mother present.

All participants were told that they could skip any questions for any reason and some chose to skip questions that prompted strong emotions or sad memories of the deceased parent.
In Study IV, interviews were conducted using the same approach as in Study I. These interviews were used to complement the data provided in the one-month follow-up questionnaires by confirming and elaborating upon the information gathered in the questionnaires. I met with parents or families at the research center or the family’s home. For two of the interviews, I was accompanied by a colleague. When more than one family member was present, they were all interviewed together. Parents and children were asked towards the end of the interview if the children could be interviewed briefly without the parent present, at which time parents agreed and left the room. Siblings were typically interviewed together. This allowed children the opportunity to say things they might not want to share with their parent. By interviewing family members together, separately, and by subsystem (i.e., siblings), more data about the family as a system was collected (Nadeau, 2001). Some parents did not have their children take part in the follow-up interview because they felt they would not be able to handle it emotionally. The children who did participate in the follow-up interviews were open and honest regarding their experience of participating in the intervention.

5.3.2. Questionnaires

The study-specific questionnaire was used in Study II and as a baseline in Study IV. It was comprised of demographics, questions about care, and family-related factors during the ill parent’s last month of life. Also included were validated scales to rate the quality of communication between the surviving parent and child/adolescent, symptoms of prolonged grief, and psychological symptoms experienced by the child/adolescent (see 5.3.2.1-5.3.2.3). The adolescent questionnaires were developed to be age-appropriate in terms of both content and length and contained fewer questions than the parent questionnaires. They also included the validated scales (see 5.3.2.1-5.3.2.3).
Parent-proxy questionnaires were similar to adolescent questionnaires, but were completed by the surviving parent on behalf of their child.

In Study IV, a short online questionnaire regarding the three sessions of the Grief and Communication Family Support Intervention was created and distributed to participating families. Parents filled in a questionnaire for themselves and for each child. Post-intervention assessment via online questionnaire occurred twice: one month and six months post-intervention. Questions were related to the content and structure of the sessions and participant perceptions of possible effects, such as their use of communication strategies taught during the intervention and if they thought relationships had improved in their family following the intervention.

5.3.2.1. Parent and Adolescent Communication

The Parent and Adolescent Communication Scale (PAC) rates the quality of communication between a parent and their child/adolescent. It is comprised of a parent form and an adolescent form and measures family communication on two scales: open family communication and problems in family communication, with each subscale consisting of 10 items. Results on the two subscales are added to get a total score for parent-adolescent communication, with higher scores indicating better quality of communication (Barnes & Olson, 1985, 2003). The PAC was forward-translated from English to Swedish as part of this study.

5.3.2.2. Prolonged Grief

The Prolonged Grief Disorder-13 Child (PG-13 Child) was completed by parents and adolescents to assess symptoms of prolonged grief in children and adolescents, respectively. The PG-13 Child is based on the PG-13 for adults (Pohlkamp, Kriebergs, Prigerson, & Sveen, 2018; Prigerson et al., 2009). The PG-13 total score used in Study II is a continuous measure calculated by summing up the symptom items, with scores ranging from 11 to 55.
5.3.2.3. Strengths and Difficulties Questionnaire

Parents completed the parent report and adolescents completed the self-report of the Strengths and Difficulties Questionnaire (SDQ). The SDQ is comprised of 25 questions divided into five subscales: emotional problems, conduct problems, hyperactivity, peer problems, and prosocial behavior. Higher scores indicate more problems. The validity of the SDQ’s five-factor structure has been supported in large-scale surveys (Goodman, 2001; Malmberg, Rydell, & Smedje, 2003).

5.3.3. The Grief and Communication Family Support Intervention

Like the Family Bereavement Program (FBP), our Grief and Communication Family Support Intervention aims to promote healthy adaptation to bereavement by improving communication between family members, reinforcing open family communication, and providing psychoeducation on grief. This is accomplished by the therapist providing information to the family about common grief reactions and communication strategies. Cognitive behavioral methods, such as skills training and role-playing, are used together with family therapy methods which focus on family relationships and emotional processing. The intervention offers modules focused on grief and communication which can be modified based on the ages of participating children (Figure 4).
5.3.4. Adherence Checklist

An adherence checklist was created and distributed to the two therapists (Study III and Study IV) to be used as a self-report of which modules were completed during each session, to evaluate fidelity. Therapists were asked to fill in a checklist for each family directly following each session. I used the same checklist when evaluating the audio-recorded sessions.

5.4. Analysis

5.4.1. Qualitative Analysis

For Study I, the first interviews were read several times and possible headings were noted in the margin. These headings were then recorded in a separate document and arranged into categories. After this open coding, the categories were arranged into higher order subcategories. Each category was named and subcategories with similar data were grouped together to form larger categories. The data in each category were then summarized to eliminate repetition (S. Elo & H. Kyngäs, 2008).
This preliminary analysis identified family communication as the most prominent and comprehensive category. At this point, the repeated interviews were conducted and transcribed. All eight interviews were read several times with a focus on verbal and non-verbal family communication and analyzed using inductive content analysis, as described above, with data being sorted into headings, coded, and arranged into categories (Elo & Kyngäs, 2008). Similarities and differences between what the four families had said were analyzed and the categories were continuously adjusted until they became clear and concise enough to describe factors that might be involved in, or related to, communication in the participating families.

The interviews from Study IV, as well as the answers to the open-ended questions in the Study IV follow-up questionnaires, were analyzed using inductive qualitative content analysis as described for Study I (Elo & Kyngäs, 2008). Open coding was conducted while reading each interview 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. Similarities and differences between the categories and within categories were discussed and adjusted until my advisors and I reached agreement.

5.4.2. Quantitative Analysis

Descriptive statistics were used to describe participant demographics and reported scores on the Parent and Adolescent Communication Scale, Prolonged Grief Disorder-13 Child, and the Strengths and Difficulties Questionnaire used in Study II, as well as the follow-up questionnaires used in Study IV.

For Study II, Spearman rho correlation coefficients were calculated, along with p values, using cluster robust covariance estimates, taking into
account that some parents answered for several children in the case of siblings. The functions rank, lm, cluster-vcov, and coeftest, from packages base, stats, multiwayvcov, and lmtest, in R version 3.5.0 were used. For adolescent self-reports, Spearman correlation coefficients were calculated, along with p values, in SPSS version 22. Spearman correlation was chosen due to the small sample size.

### 5.4.3. Fidelity

Fidelity was assessed using five domains as defined by the National Institute of Health’s Behavioral Change Consortium (NIH BCC) guidelines for measuring treatment fidelity: study design, provider training, delivery, receipt, and enactment (Borrelli, 2011; Robb, Burns, Docherty, & Haase, 2011). Study design ensured that the study adequately tested the study hypothesis. The audio recordings and adherence checklists were used to check for consistency of design and delivery, as well as to record deviations from the study protocol or intervention manual. Therapist training examined the quality and standardization of training for all therapists providing the intervention, which ensured that they were both trained using the same criteria and were recruited based on their education, experience, and cultural knowledge. Assessing delivery included documenting intervention differentiation, breaches in protocol, and adherence to the intervention manual using the adherence checklists, audio recordings, follow-up questionnaires, and interviews. Receipt and enactment were assessed using participant self-reports from the follow-up interviews and questionnaires. Receipt assessed each participant’s level of understanding, demonstration of knowledge, and ability to use skills taught during the three intervention sessions. Enactment measured each participant’s ability to apply what they learned during the sessions to their daily family communication upon completion of the intervention (Borrelli, 2011; Robb et al., 2011).
6. Ethical Considerations

This research project was approved by the Regional Ethics Committee DRN 2016/1192-31/1. Studies III and IV were also registered on clinicaltrials.gov under the Unique Protocol ID DRN 2016/1192/31/1. The research was conducted in accordance with the Helsinki Declaration (World Medical Association, 2014). Public interest in this project includes learning more about how to best support bereaved families so that interventions can be designed for families with children who have lost a parent to cancer, in order to reduce or alleviate the distress of parentally bereaved families in the future. However, there are many ethical dilemmas related to this research project.

Bereaved individuals are a vulnerable group and although no provisions exist for recruiting bereaved adults and obtaining their informed consent, special consideration is needed (Steeves, Kahn, Ropka, & Wise, 2000). Participants in Study I were recruited via medical records and health care personnel who were familiar with the families I contacted. A common problem with using medical records is that the contact person listed is not necessarily the next of kin and therefore may not be a bereaved family member. Furthermore, it is likely that neither the patient nor the contact person have given permission for the medical records to be used in research (Steeves et al., 2000). By involving health care personnel who were familiar with the families, I was able to eliminate one of these problems, as the nurses and counselors who had worked with a patient could confirm who the deceased patient’s spouse was and if they had children. They could also guess which patient’s families would be more open to being contacted for research purposes, although this could be seen as gatekeeping. It might have been better to have health care personnel directly contact bereaved families that met the inclusion criteria. However, this would have limited my control over how sensitively the families were approached and what information they received about the study (Steeves et al., 2000).
Since the research project dealt with sensitive life events and sensitive personal data, namely psychological health after losing a parent to cancer, the research group decided that the surviving parent's consent would be required even for adolescents who were 15 years or older – who can legally consent for themselves – as the parent would know best if their child was mature and emotionally stable enough to participate in the project without their psychological health or wellbeing being affected. Some parents did call me during recruitment to discuss the pros and cons of their children and adolescents participating, including the potential impact that participation could have on their child’s psychological health, before deciding whether or not to allow their child to participate. However, this may have resulted in parents acting as gatekeepers, implying that some adolescents who were older than 15 years and would have liked to participate in the study may never have been asked because their parent did not want them to participate. Once parental consent was obtained, consent was also obtained from adolescents ages 15 years and older in accordance with the “Act on Ethical Review of Research that Concerns People” Swedish Code of Statutes [SFS] 2003:460. This same law states that children under 15 years must have informed consent from their legal guardian in order to participate in a research study. Therefore, clear documents were made for the adults who participated, where they signed to consent not only for their own participation but also for their children’s participation. All families were informed that counselors and nurses were available to help participants through any emotional issues which might arise during participation.

Furthermore, parents were asked to provide an age-appropriate information letter to their child or adolescent (The Swedish Research Council-Gustafsson, Hemerén, & Pettersson, 2011; The Swedish Research Council). As researchers, we could not be certain that the parents shared this information with their children or that the children understood the information in the letter.
Similarly, an age-adjusted self-report questionnaire for adolescents ages 12 years or older was used. Adolescents where informed in the beginning of the questionnaire that they could skip questions if they wanted to, but we have no way of knowing if they skipped a question because it was too sensitive, they could not decide what to answer, or they did not understand the question because it was not appropriately adapted for their age. Information letters and questionnaires were adapted based on developmental psychology, i.e., what a typical 12-year-old would be able to understand based on a typical developmental trajectory (Erikson, 1950; Piaget, 1964). These decisions were informed by the research group’s experience of working with children and adolescents, but it is still a subjective judgment. One way to ensure this was done accurately was by face-to-face testing the questionnaires with children, adolescents, and parents.

This face-to-face testing also helped to ensure that the majority of problems with the questionnaire were corrected before it was used. This included ensuring that questions were relevant, not phrased in a leading manner, and comprehensible, with relevant response alternatives (Forsman, 1997). In accordance with the Swedish Personal Data Act, participants in this project were informed about what personal data was used or stored, even though a code key was used to de-identify the research subjects.

Earlier studies have indicated that participation in research may lead to positive experiences among the participants, for example by receiving attention and validation, and being given the opportunity to make their voices heard and to help others in a similar situation. Moreover, participants reported that completing the questionnaire about everything they have gone through felt therapeutic (Kreicbergs, Valdimarsdottir, Steineck, & Henter, 2004; Udo et al., 2019). It may be presumed that this research project likely provided participants with similar experiences.
7. Results

7.1. The Importance of Open Communication in Parentally Bereaved Families

Study I laid the foundation for the development of the Grief and Communication Family Support Intervention by identifying family communication as an important focus area which seemed to affect family functioning and wellbeing. Parents emphasized the importance of open and honest communication with their children and especially the importance of transparency regarding their own emotions. For example, telling the children if they were tired or stressed made communication easier, according to the parents, and often resulted in less conflict between family members. Parents were also eager to praise their children’s successes, thank them for sharing their thoughts and feelings, and provide comfort and support. Children frequently used non-verbal communication, such as drawing pictures or writing thank you cards or notes for their parents and siblings to show appreciation or cheer someone up who was having a bad day.

Results from Study I and Study II provided evidence of an association between family communication and psychological health, which highlighted the importance of focusing on communication during the intervention. These results are presented below according to participant age, where children are 4–11 years old and adolescents are 12 years and older.

7.1.1. Children

In Study I, new challenges for the family seemed to affect children’s psychological health by increasing conflict and at times negative emotions. An example of this was the parents’ struggle to divide their time equally or fairly between their children. Parents and children stated that a failure to do this led to
arguments, hurt feelings, and competition between siblings for their parent’s attention. Children expressed that while they logically understood the practical difficulties their parent was now facing, emotionally they were upset and frustrated by receiving less direct attention or having to wait longer for their emotional needs to be met.

Another example of a potential link between communication and psychological health in Study I was when the parents explained that once the child began speaking about their deceased parent, they could seize the opportunity and encourage the child to continue talking about their feelings surrounding the death or they could also choose to let the child say what he/she wanted to say without encouraging expression of deeper emotions. This indicated that how the parent chose to speak with their child might affect how the child processed their emotions. According to the parents, which strategy they chose was often situationally determined. For example, if the child started crying at the grocery store, parents typically elected to use the second strategy, calming the child down as quickly as possible. In these situations, parents usually broached the topic again later, when they were at home, to help the child process their emotions in a more suitable environment.

Parent-proxy reports from Study II indicated that better communication between the parent and child was associated with fewer psychological health problems in children aged 4 to 11 years, with more open communication being associated with fewer conduct problems and less hyperactivity. Furthermore, increased problem communication was associated with a higher instance of conduct and emotional problems. Parent-proxy reports further showed that the Emotional Problems subscale was significantly positively correlated with symptoms of prolonged grief for children ages 4–11 years.
7.1.2. Adolescents

Similarly, parent-proxy reports for adolescents suggested that better communication between the surviving parent and adolescent was associated with fewer psychological health problems in the adolescent following a parent’s death from cancer. Unlike the results for the younger children, open communication was associated with the adolescent more often engaging in prosocial behavior, rather than being associated with conduct problems. Likewise, less problem communication was associated with more prosocial behavior. On the other hand, increased problem communication was associated with greater occurrence of conduct and emotional problems. Like the parent reports for children, parent reports for adolescents showed that the emotional problems subscale was significantly positively correlated with symptoms of prolonged grief for adolescents. There was also a significant correlation between parent-reported prolonged grief symptoms for adolescents and the SDQ total difficulties score.

Adolescent self-reports in Study II indicated that adolescents experienced low-quality communication with their parent and abnormal or borderline abnormal psychological health. Self-reported conduct problems were associated with lower quality of parent-adolescent communication as measured by PAC total score, including higher scores on problem communication and lower scores on open communication. Unlike the results from the parent reports, there was no association between adolescents’ self-reported emotional problems and quality of parent-adolescent communication. Adolescents’ self-reports in Study II also showed that symptoms of prolonged grief were associated with emotional as well as conduct problems, indicating that children and adolescents with more emotional problems may be experiencing more symptoms of prolonged grief. Parent-proxy and adolescent self-reports from the interviews in Study I and Study IV, as well as responses to open questions in Study II (which I read, but did not analyze as a part of this research project),
indicated that many adolescents were engaging in risk-taking behaviors, such as alcohol and drug use or skipping school. Reasons for this included a need for distraction, trying to numb one’s feelings, and wanting to withdraw from one’s social network.

7.1.3. Parents

In Study I, parents stated that they felt the need to take on family roles and responsibilities that the deceased parent had previously had, such as maintaining a balance between discipline and emotional support, or to know what rituals the other parent may have had with the child, such as buying a special snack after school. Parents’ adjustment to these new parenting roles often led to increased family conflict as they struggled to fill the empty role and children struggled to communicate their needs and expectations of how that role should be filled. Parents further struggled to realize or admit that they couldn’t manage everything on their own and subsequently ask for help from their social network of family and friends. Some parents felt ashamed that they weren’t “enough” and others felt that needing to ask for help conflicted with their self-image as an autonomous capable adult.

7.2. Developing the Grief and Communication Family Support Intervention

The manual used in Study III was developed in collaboration with three family therapists. It consisted of three sessions, all of which were planned to be ninety minutes each. When testing the manual with two families, many of the sessions took longer than the allotted ninety minutes and the therapists elected to pause halfway through each session for coffee, tea, snacks, and bathroom breaks, which seemed to help the participating family members stay focused for the entire session.
The therapists reported that it was easy to follow the manual without any major deviation and felt that the participating families responded well to each session. However, the therapists made a few suggestions for improvements to the manual, such as making the font size larger, and highlighting the sections the therapists were expected to read out loud, which they felt would make it even easier to follow the manual in future studies.

Following the completion of Study III, some changes were made to the content of the intervention manual before conducting Study IV. Originally, session 1 included a module called “Introduction to I-messages”. This module was removed, as it was repeated in session 2 when I-messages were discussed and practiced in depth. Another change to session 1 was that “Psychoeducation about what good communication is” was moved to appear immediately after “Psychoeducation about what can make communication more or less difficult”, because the latter addressed some barriers to communication, such as finding the right time to talk. No changes were made to session 2.

The module on problem-solving in session 3 seemed to put undue pressure on the children to spontaneously come up with a problem they needed help solving. Initially comprised of a step-by-step guide for problem-solving involving a concrete skills training exercise, the module was condensed to provide a more general overview of problem-solving strategies and discussion with the family about what could be useful in their family. The focus was shifted to a discussion of what types of problems would be appropriate for a child to solve on their own and when it would be appropriate or even necessary for a parent to help the child solve a problem.

During the revision process, it was decided that the exercises and role-play should be conducted more explicitly by the therapists, rather than having a process-oriented discussion. Reasons for this included keeping younger children active and engaged, as well as allowing the family to practice the skills which were being taught. The revised manual was used in Study IV.
7.3. Evaluating the Grief and Communication Family Support Intervention

During follow-up phone calls, the participating parents in Study III stated that they found the intervention to be meaningful and that their children spoke more about the deceased parent following the intervention. Participants in Study IV reported several beneficial outcomes at the one-month and six-month follow-up assessments, including improved family relationships and family communication. Children and adolescents explained 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. Parents and children also reported that they had learned new communication skills and gained new knowledge regarding other family members’ individual experiences, for instance of anxiety or guilt, which the rest of the family had not been aware of previously. Participants felt these types of revelations helped to improve communication and relationships within the family by creating a shared family narrative.

According to the results from the one-month follow-up questionnaire, most parents believed they and their children had received “some” or “a lot of” information regarding each topic specified and that they had practiced most of the communication strategies taught during the sessions. Participants also expressed an appreciation for learning more about grief and talked about how they were continuing to use the communication strategies they had learned. The strategies that most family members stated they were using in their daily family communication included: sharing thoughts and feelings, showing appreciation for one another, I-messages, and active listening. Responses to the six-month follow-up questionnaire indicated that I-messages and active listening were the two strategies most frequently used by parents and children.
Participants seemed to have positive experiences during the three sessions. Most parents indicated that the intervention was comprised of an adequate number of sessions and that 90 minutes was a good length of time for each session with a break in the middle for water, coffee, tea, and snacks. Parents and children stated that they would recommend the intervention to other bereaved families, mainly because they found the intervention to be meaningful or beneficial to their own family and believed other bereaved families with children would experience the same benefits.

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. One parent thought an introductory session with just the parent would have been helpful. A main topic of discussion for all the families was how long after the parent’s death the sessions should be offered, with the majority of participants indicating that two years after the parent’s death would be the best time for them to participate in the intervention.

In Study IV, approximately half of all sessions were completed exactly as intended. For session 1, therapists reported completing 96% of the modules, while the independent rating of adherence for session 1 was 84%. For session 2, therapists reported completing 78% of the modules and the independent rating resulted in a 75% rate of adherence. The therapist rating and independent rating of adherence for session 3 were both 86%, indicating a high rate of adherence for all three sessions and a high level of agreement between the therapists’ completed checklists and the independent rating of adherence based on the session recordings.
8. Discussion

Open family communication was identified as an important factor for family adjustment and psychological health. Importantly, communication in some parentally bereaved families may involve more conflict, which may also affect child and adolescent psychological health. Family communication was therefore chosen as a main focus of the Grief and Communication Family Support Intervention, which was adapted from the group-based Family Bereavement Program, tested with two families, and modified based on participant and therapist feedback. Results from testing the Grief and Communication Family Support Intervention with a sample of ten families indicated that it might be useful in improving family communication and relationships, although testing with larger samples is still needed.

8.1. The Importance of Open Communication in Parentally Bereaved Families

The most important result from Study I was how much the parents emphasized the importance of open and honest communication with their children. Parents explained that taking the time to explain how they were feeling or why they had made a particular decision made communication with their children easier, which in turn made daily life less stressful. Results from Study II provided further evidence of an association between family communication and psychological health, which reinforced the importance of focusing on communication during the intervention. Previous research has shown that families who are better able to openly communicate their thoughts and feelings and allow each family member to express grief in their own unique way typically cope with loss more effectively (Davies, Spinetta, Martinson, McClowry, & Kulenkamp, 1986; Kerr & Bowen, 1988; Lamberti & Detmer, 1993). Specifically, bereaved children are more likely to adjust positively to the loss of a
parent if they believe that their family environment encourages open sharing and expression of thoughts and emotions, as the expression and acceptance of sad or confused emotions helps children to develop a personal understanding of a loss (Green & Connolly, 2009; Howell et al., 2016). Furthermore, families who communicate openly and express their emotions have been found to have lower levels of depression, anxiety, and post-traumatic stress following a parent’s illness and death (Howell et al., 2016; Karlsson, Andersson, & Ahlström, 2013; Shapiro et al., 2014).

Following the death of a parent, new challenges for the family seemed to affect children’s psychological health by increasing conflict and, at times, negative emotions. An example of this was the parents’ struggle to divide their time equally or fairly between their children. Parents and children stated that a failure to do this led to arguments, hurt feelings, and competition between siblings for the parent’s attention. Wolchik et al. (2006) similarly found that parentally bereaved children are likely to spend less high-quality time with their surviving parent as the parent is struggling to manage their own grief and psychological distress while adjusting to their new role as a single parent. When this happens, children likely receive less attention for positive behaviors, which may damage their sense of self-worth and potentially lead to the child developing mental health problems (Wolchik et al., 2006).

Another example of a potential link between communication and psychological health in Study I was when the parents explained that once the child began speaking about their deceased parent, they could seize the opportunity and encourage the child to continue talking about their feelings surrounding the death or they could choose to let the child say what he/she wanted to say without encouraging expression of deeper emotions. Related to this, Field et al. (2014) found that communication between a child and the surviving parent about the deceased parent was positively associated with children’s adaptive grief responses. Research has shown that helping children
regulate their emotions through dialogue about the deceased parent is important because the death of a parent in childhood can lead to poor emotion regulation skills and a negative internal working model of the self, which often results in conduct and emotional problems as well as reduced self-esteem (Collins, Guichard, Ford, & Feeney, 2004; Riggs, 2010). Reminiscing about emotional experiences is believed to help children develop emotion regulation skills by providing an opportunity for reflection and re-evaluation of the experiences, which helps children to process their emotions (Quas & Fivush, 2009; Salmon & Reese, 2016; van Bergen & Salmon, 2010).

Adolescents were less likely than children to talk about their deceased parent with their family and reported in interviews that they usually turned to their friends for emotional support. This is likely due to the fact that adolescents have typically established some degree of autonomy from their parents, which makes them more reliant on friends and peers (Balk, 2014; Erikson, 1950). One reason why the parent’s communication skills are so important for their child’s wellbeing is because acknowledging a child’s feelings as legitimate and providing constructive ways to reframe the child’s experiences while reminiscing likely enhances the child’s feelings of security and self-efficacy. In contrast, dismissing the child’s feelings as either illegitimate or focusing on the negative emotions involved in the event, without providing ways to cope with the negative emotions or reframe the experience, likely wears down the child’s sense of security (Quas & Fivush, 2009). This is likely also true for adolescents when reminiscing with their friends, but more research is required to better understand how parentally bereaved adolescents communicate with and receive emotional support from their peers.

Parent reports from Study II indicated that better communication between the parent and child was associated with fewer psychological health problems in children and adolescents, especially with regards to problem communication and conduct problems. Similarly, adolescent self-reports
indicated that conduct problems were associated with lower quality of parent-adolescent communication, as measured by PAC total score, including higher scores on problem communication and lower scores on open communication. Similarly, Bylund Grenklo et al. (2014) found that self-harm behaviors were more common in bereaved adolescents who reported low levels of family cohesion. From a family systems perspective, cohesion is the balance of separateness and togetherness between family members. Families with a balanced level of cohesion tend to have more open communication (Olson, 2000). This is also in line with Granqvist et al. (2017), who note that major separation from an attachment figure or excessive stress as experienced by the child or adolescent, such as the death of a parent, may cause the child or adolescent to exhibit disorganized behaviors such as conduct and emotional problems. Further, parents of children exhibiting these types of behaviors are more likely to use problem communication, including hostility, intrusiveness, and/or emotional detachment (Moss, Rousseau, Parent, St-Laurent, & Saintonge, 1998). It is difficult to know if the disorganized behaviors develop before or after the increase in problem communication, and how these types of problems develop may depend on other family or individual factors, which are outside the scope of this research project. Based on my clinical experience, in most cases when children have developed conduct problems, conflicts such as arguments about the child’s behavior and meetings with school personnel also increase, which may further reinforce the conduct problems in the child as well as problem communication in the family.

Some parents felt ashamed that they weren’t “enough” and others felt that needing to ask for help conflicted with their self-image as an autonomous capable adult. This is in accordance with the assumption of Neimeyer et al. (2002), that the loss of a romantic partner often undermines an individual’s self-identity and self-concept, which causes the individual to need to redefine themselves in relation to their social world. It can be especially difficult for
bereaved individuals to adapt and move on if the death disrupted their sense of self-identity or sense of purpose (Neimeyer et al., 2002). Most parents who participated in this research project talked about how caring for their children gave them a sense of purpose as they were all their children had left. This sense of purpose may have helped them to overcome or cope with their grief, as well as their struggle with their self-identity, so as to not fall apart and negatively affect their children. This result further indicates that many surviving parents who participated in this research project were likely in the phase of reorganization (see 2.3.2), where they are trying to reorganize or even redefine their internal representation of themselves, others, and the world around them while coping with their grief, in order to adapt to daily life without their deceased partner (Fraley & Shaver, 2016).

8.2. Development of the Grief and Communication Family Support Intervention

The Grief and Communication Family Support Intervention is an adaptation of group-based modules from the Family Bereavement Program (FBP) to family-based modules relating to grief and communication. Looking back on the development of the Grief and Communication Family Support Intervention, I realize that I more or less followed the Campbell et al. (2000) phased approach to developing complex interventions, although I did not know it at the time. This approach may better explain the development and adaptation of the intervention. In keeping with the Campbell et al. (2000) five-phased approach, I can see that I first identified evidence that the intervention might have the desired effect. Campbell et al. (2000) call this the pre-clinical phase. My next step was to decide what to include in the intervention. I did this largely based on what parents and children reported during the interviews in Study I, the literature I had gathered on interventions for bereaved families and children, and through my collaboration with Professor Irwin Sandler. In the Campbell et
Campbell et al. (2000) approach, this is considered to be phase I, which has the goal of defining the components of the intervention using qualitative testing. In phase II of the Campbell et al. (2000) approach, the trial and intervention design are defined, outcomes are determined, and feasibility is tested through exploratory trials. This essentially describes the initial test of the Grief and Communication Family Support Intervention which was conducted in Study III and the second test conducted in Study IV. Phases III and IV of the Campbell et al. (2000) approach take into account methodological issues related to a main trial such as sample size, inclusion criteria, and methods of randomization and promote effective implementation. Conducting a randomized trial (phase III) and making a plan for implementation (phase IV) were goals of this project which were not achieved due to the limited sample size. However, issues of inclusion criteria, sample size, and methods of randomization were discussed before discovering that the sample for Study IV would be limited to ten families.

My theoretical knowledge and clinical experience helped me to identify modules in the FBP manual which would be especially important to include in the Grief and Communication Family Support Intervention. The module in session 3 on problem-solving was one example of this. Problems arise in all families and for all individuals. Families that use more open communication tend to engage in problem-solving more regularly (Balk, 2014). Furthermore, problem-solving through cooperative negotiation at the time of conflict may help to maintain attachment bonds (Kobak & Duemmler, 1994). Sharing positive emotions was another important module included in the Grief and Communication Family Support Intervention. This module was included and emphasized because parents and children in many families may try to hide how they feel from each other because they do not want to concern or burden one another. Hiding feelings from each other may lead to tension, misunderstandings, or conflict. Family members need to feel comfortable sharing any feelings they may have, before they can respond with feelings that
suit the situation; this is called affective responsiveness (Balk, 2014). Affective responsiveness is important because it is one of the main ways that family members support each other. In order to achieve affective responsiveness, family members need to care about how others are doing and listen to each other (Peterson & Green, 2009). In other words, open communication is key to building and maintaining affective responsiveness. Similarly, because the attachment bond is an emotional bond which is strengthened by positive emotions and having fun together, modules such as “Sharing positive emotions” and “Family time” may have helped to further strengthen attachment bonds between the participating parent and children (Kobak & Duemmler, 1994).

8.3. Evaluating the Intervention

Participants in Study III and Study IV indicated that the intervention was meaningful as it helped children to speak more openly and more frequently about their deceased parent and was believed by participants to have improved relationships and communication in their family. Improvements in communication and family relationships may be evidence of family meaning making. Therapy, counseling, and other supportive psychosocial interventions prompt the articulation and elaboration of the family’s narrative of loss in a way that promotes a new sense of coherence, continuity, and consensual validation of identity (Neimeyer, 2001a). When the family’s story is heard over and over again, the therapist looks for subtle changes in the story. These changes represent the development and evolution of family meaning making and typically indicate family progress (Nadeau, 2001). When taking part in the Grief and Communication Family Support Intervention, family members told their story of the parent’s death multiple times. How the families told their story may have been evidence of the level of openness in the family, or their willingness to engage in meaning making with other family members (Nadeau, 2001), although this was not studied as a part of this research project.
Learning new communication skills was a main outcome of Study IV. According to Bowen (1974), even a slight improvement in family communication can cause dramatic shifts in how family members express their feelings. Children and adolescents reported that they felt more comfortable coming to their surviving parent with a problem and expressing negative emotions. Open communication is believed by attachment theorists to help form and reinforce secure attachment bonds between parents and children. Moreover, they believe that having a more secure attachment to one’s parent tends to make children and adolescents more comfortable asking questions and openly expressing their fears and concerns (Quas & Fivush, 2009; Zeifman & Hazan, 2016).

Parents and children also reported that they gained new knowledge regarding other family members’ individual experiences. Liew and Servaty-Seib (2018) found that family communication about differing grief reactions was positively associated with family satisfaction such as feeling acknowledged, accepted, and included in the family. Similarly, Barnes and Olson (1985) found that families with good parent-child communication rated themselves higher on measures of family satisfaction. In other words, open communication and family satisfaction seem to be associated, but which comes first is unclear. It may be that open family communication is more common in families that already have higher levels of family satisfaction, more cohesion, and healthier relationships between family members (Olson, 2008).

Parents stressed the value of being able to meet with the therapist after work or on the weekends, which is not common practice in the Swedish health care system. In order for this to become more commonplace, policies would need to be changed at the macrosystem level, allowing or encouraging service providers to meet with families during evening and weekend hours. The first decision to be made, however, would need to be which service providers should be offering bereavement support such as the Grief and Communication Family
Support Intervention. In the public health model of service differentiation, the first level of service delivery is universal, targets all bereaved people, and may include compassion and information provided through phone calls or brochures to all bereaved families. In many countries, this is done by volunteers, which helps to make formal palliative care and bereavement support professionals more available for complex cases (Breen et al., 2014). In Sweden, however, follow-up phone calls are conducted by palliative care professionals (National Board of Health and Welfare, 2016b), which takes up a great deal of their time; this task could easily be taken over by trained volunteers.

The second level of intervention is meant to be preventive. It selectively targets people at risk of bereavement complications and may involve grief counseling provided by trained professionals (Aoun et al., 2012; Breen et al., 2014; Neimeyer & Currier, 2009). This is the level where the Grief and Communication Family Support Intervention could be implemented, as parentally bereaved children would likely be considered a risk group in need of preventive care (Ayers et al., 2014; Berg & Hjern, 2016; Spuij et al., 2015; Worden & Silverman, 1996). In Sweden, this could involve pediatric primary care centers or county-run social services, where counselors and family therapists are already employed. Implementation of the Grief and Communication Family Support Intervention would need to begin with a top-down approach in the macrosystem, whereby the central government determines the core aspects of policies dictating which service providers would be responsible for offering the intervention and what reimbursement model would be used. This would then need to be complemented by a bottom-up approach in the exosystem in order to strengthen policy implementation and compliance at the organizational and/or regional level (Bronfenbrenner, 1977; Buse, Mays, & Walt, 2005).

There was a high level of fidelity when testing the intervention with regards to study design, provider training, delivery, receipt, and enactment,
which means that the intervention was implemented as intended (McGee, Lorencatto, Matvienko-Sikar, & Toomey, 2018). Treatment fidelity is important because it can impact the internal and external validity of a study as well as effect size and statistical power. If the intervention being tested does not adhere to the design protocol and intervention manual, the results will not be truly informative with regards to the utility of the intervention, as it will be impossible to know if the results were due to the intervention or external factors. Furthermore, if the standardized protocol is not followed, the study cannot be replicated accurately (Resnick et al., 2005). Having a high level of fidelity therefore implies that the results of Study IV are likely based on the intervention itself rather than external factors and makes it easier to replicate the study.

## 8.4. Methodological Considerations

### 8.4.1. Validity

In qualitative research, validity is typically concerned with the researcher’s own perspective or point of view, as well as the participant’s point of view. Because of this, each researcher’s unique paradigm assumptions and world view help to influence their choice of procedures and methodology (Creswell & Miller, 2000). This differs from quantitative research, which is mostly concerned with the validity of inferences made based on psychometric instruments and validity of study design including construct, criterion, and content validity (Creswell & Miller, 2000).

#### 8.4.1.1. Qualitative Research

Validity in qualitative research has to do with the trustworthiness of the inferences and interpretations made by the researcher, including credibility, dependability, and transferability (Creswell & Miller, 2000; Graneheim & Lundman, 2004). When assessing credibility, it is important to consider how well the data collection and analysis processes have addressed the intended
focus of the research, while taking into account the selection of context, participants, and methodology for data collection (Graneheim & Lundman, 2004). Participants in Studies I and III were selected using convenience sampling. In Study IV, participants were recruited through Study II. Purposive sampling in terms of children’s development stage would have yielded more knowledge in all four studies by providing a more complete and nuanced picture of family experiences.

Credibility may be facilitated or hindered during the analysis process. Using representative quotes from participants and seeking agreement amongst co-researchers and participants were two methods used during Studies I and IV to increase the credibility of the findings. This process requires that everyone agree that the way the data is sorted makes sense, rather than checking to see if everyone sorts the data in the same way (Graneheim & Lundman, 2004). Studies I and IV used thick rich descriptions of the settings, participants, and categories, which helps readers to feel as if they have or could have experienced the events and details described in the text. Study I also used member checking, where credibility is enhanced by taking the data and interpretations of the data back to participants so that they can confirm the credibility and accuracy of the information (Creswell & Miller, 2000). This was done during the repeated interviews in Study I and during face-to-face validation of the study-specific questionnaire used in Study II, to ensure that categories for Study I made sense and that questions included in the questionnaire were relevant to participant experiences.

Dependability is concerned with the degree to which data change over time and with alterations in the researcher’s decision-making throughout data collection and analysis. One example of this in Studies I and IV was that follow-up questions evolved from one interview to the next (Graneheim & Lundman, 2004). This was due to my own growing confidence, new observations with regards to similarities and differences between the participating families, and
new information gained from reading relevant literature. In order for these changes to be considered dependable, I maintained an open dialogue with my three advisors throughout the entire data collection and analysis processes (Graneheim & Lundman, 2004).

Transferability refers to how well or accurately the results can be applied to other groups or settings and is limited in all four studies due to the small sample size, with participants coming from a specific culture and context (Graneheim & Lundman, 2004). This implies that the results may be transferable only to other families in Stockholm county who have lost a parent to cancer in the past 1–3 years and not to families in other geographical regions or to families who lost a parent to another cause of death.

8.4.1.2. Quantitative Research

Quantitative research aims to divide phenomena into common categories which may be applied to all participants and describes information at a group level while ignoring individual differences (Winter, 2000). Study II had a small sample size and therefore low statistical power. Therefore, despite the high level of significance, results from Study II may not be generalizable to all children and adolescents who have lost a parent to cancer. This study is therefore lacking in external validity or the extent to which results can be generalized. Internal validity, or whether findings and results relate to and are caused by the phenomena being studied rather than external influences, is also lacking in Studies II and IV (Winter, 2000). The significant correlations found in Study II give some hope of internal validity, but correlation does not equal causation. Having a larger sample in Study IV might have helped to establish internal validity, as teaching participants new communication skills would likely have improved their communication (qualitative reports from participants indicated that it did) and would in turn lead to improved psychological health, assuming my hypothesis is correct. The use of audio recording and independent evaluation of adherence in Studies III and IV helped to confirm fidelity with
regards to study design and delivery, thereby helping to ensure internal and external validity. 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. By using validated instruments in the study-specific questionnaires, content validity – the extent to which an instrument accurately measures all aspects of a construct – as well as construct validity – the extent to which an instrument can measure the intended construct – were both increased for Studies II and IV. However, these instruments were not necessarily validated with bereaved Swedish families, so it is possible that culture or the circumstance of bereavement affected validity. Furthermore, to improve face validity, participants and other researchers were asked to comment on the study-specific questionnaire with regards to whether, in their opinion, the questions included measured the intended concepts (Heale & Twycross, 2015).

A methodological consideration for Study II was the use of PAC for parents’ communication with children under the age of 12 years. The scale was developed to be readable by children as young as 12 years, but information regarding age restrictions for the use of the parent report was not found. The research group decided that the parent report could be used for both age groups in order to have a consistent measurement for communication, since the age limit seemed to be due to issues of comprehension and readability for the child or adolescent.

In Study II, there was a lack of agreement between parent and adolescent reports of communication and psychological health for most of the families. Self-report is typically considered the best way to assess health-related quality of life indicators, such as measures of psychological health, in adults and in adolescents assuming they have reached a certain age and developmental level, whereas the usefulness of parent-proxy reports has been shown with regards to younger children (Erhart, Ellert, Kurth, & Ravens-Sieberer, 2009; Theunissen et al., 1998). When studying children and adolescents, a multidimensional
assessment approach with multiple informants is usually valuable and may help to reduce false negatives (Van Roy, Groholt, Heyerdahl, & Clench-Aas, 2010). Lack of agreement between parent-proxy and adolescent self-reports may indicate that parents and adolescents are actually reporting different information which is valid from their perspective and does not necessarily indicate bias or a lack of awareness or judgment on behalf of one of the informants. Moreover, the amount of agreement between parent and adolescent reports does not indicate whether their reports are valid and accurate or not (Erhart et al., 2009; Van Roy et al., 2010). Furthermore, parent-proxy reports may provide information which complements the adolescent’s self-report. Several factors have been found to potentially influence agreement between parent-proxy and adolescent self-reports, including amount of time spent together, parental engagement and quality of parent-adolescent communication (Van Roy et al., 2010). Additionally, previous research has shown that Scandinavian adolescents often report more symptoms when using self-report questionnaires than participants from other countries, while their parents tend to report fewer symptoms using parent-proxy questionnaires (Broberg et al., 2001; Heyerdahl, Kvernmo, & Wichstrøm, 2004; Rescorla et al., 2007; Van Roy et al., 2010). This was the case in Study II. Generally speaking, the use of questionnaires to assess psychological health may involve some degree of response bias, as participants unconsciously try to report more socially desirable answers and therefore tend to avoid extreme values. However, questionnaires are more time- and cost-effective than interviews (Cohen, Swerdlik, & Phillips, 1996).

8.4.2. Recruitment

Specific regulations from The National Board of Health and Welfare and Statistics Sweden affected my ability to recruit participants for Studies II and IV, as families with separated or divorced parents and adolescents who had moved out of the family home were excluded, thus limiting the number of families
contacted. The rationale given for these criteria was that there was a possibility that the child or adolescent had not had contact with their deceased parent and therefore was not aware of the deceased parent’s illness or death and that learning such information could be traumatic or harmful to the child.

The fact that the research group could not contact participants directly during the recruitment process may have affected the response rate for Study II, and thereby Study IV, as the participants had to actively contact the research group. In a previous study, participation was markedly raised through personal contact during recruitment (Eilegard et al., 2013). The requirement of active participation on the part of participants during the recruitment process may also have led to a more biased sample, which included only families already possessing adequate coping skills and possibly higher levels of psychological health and communication.

Reasons for declining to participate in all four studies included lack of energy and reluctance to re-awaken negative feelings. This further indicates that our sample was biased towards participants who were better able to cope with their bereavement (Stroebe & Stroebe, 1989).

### 8.4.3. Author Involvement in Assessing Adherence

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 as a weakness due to my own bias. McGee et al. (2018) defines fidelity as the extent to which the intervention is implemented as the developer intended. In light of this, my involvement in this process makes more sense. As the lead developer of the Grief and Communication Family Support Intervention, I would be the only person fully aware of my own intent with regards to development and implementation of the intervention and therefore most qualified to assess adherence, thereby ensuring
that my vision of what this intervention could and should be was executed as accurately as possible.

8.4.4. **Strengths and Limitations**

Strengths of Studies I, II and IV include speaking directly with children and adolescents during interviews, collecting self-report questionnaires from adolescents, using repeated interviews in Study I and conducting interviews as a complement to the follow-up questionnaires in Study IV. This made it possible to present more child-centered results and a more complete picture of family communication, bereavement, and experiences of participating in the intervention.

Another strength of Studies III and IV was the adaptability of the manual to children of different ages. The unanimously positive response of all participants in Study IV regarding the intervention gives promise that larger studies of the Grief and Communication Family Support Intervention will show positive results with regards to fidelity and meaningfulness to the participating families.

A limitation of Studies II and IV was that we do not have information on the family members’ history of psychological health prior to the loss. Another limitation is a lack of information regarding additional stressors, such as other losses and financial problems in the family, which may affect the families’ psychological health.

8.5. **Conclusions**

The family’s struggle to adjust to life without the deceased parent may lead to increased family conflict, a type of problem communication. Increased problem communication was associated with increased conduct problems in children and adolescents. While correlation does not equal causation, the association was significant. This implies that helping families find ways to
negotiate complex changes to their everyday lives so that they will be more likely to adjust and adapt in healthy ways, potentially through the Grief and Communication Family Support Intervention, is likely to improve psychological health and communication in bereaved family members and may even reduce problem communication and conduct problems.

Two tests of the Grief and Communication Family Support Intervention indicated that the intervention improved family communication and relationships in the participating families. While it is too soon to generalize these findings to all parentally bereaved families, these results offer hope that larger studies of the Grief and Communication Family Support Intervention would produce similar results.

Children and adolescents seemed to seek support from different sources, namely parents versus friends. Developmentally, this makes sense. If the child’s or adolescent’s reminiscing and sharing of emotions is met with understanding and they are further encouraged to share their emotions and experiences, they may be more likely or better able to regulate their emotions and engage in an adaptive healthy grieving process. For this reason, society as a whole should be educated regarding the needs of parentally bereaved families so that friends, teachers, neighbors, and the family’s wider social network can all act to best support family members who are grieving the death of a parent.

Similarly, educating society about the needs of parentally bereaved families may increase understanding and support for the surviving parent as they struggle to balance their self-image as a capable autonomous adult with their need for help from their social network. Many parents expressed reluctance and difficulty with regards to asking for help and support. If the community is better informed of these parents’ needs for social, emotional, and practical support, members of the community may be more likely to freely and spontaneously offer support, thus reducing the parent’s stress, burden, and struggle with self-identity.
9. Implications

This research project sheds light on the unique experiences of parentally bereaved families with regards to family communication and psychological health. By becoming more aware of the struggles faced by parentally bereaved families, clinicians may be better able to prepare their patients’ families for bereavement by educating them on common struggles and changes to family life as well as typical grief reactions for parents, adolescents, and children. Furthermore, results confirm that communication is an important focus of clinical interventions for parentally bereaved families, as it is associated with child and adolescent psychological health.

The results of this project further indicate that the Grief and Communication Family Support Intervention may help to improve communication and family relationships in parentally bereaved families. More research with larger, more diverse samples, preferably using an RCT or wait list design, is needed to confirm that these results are caused by the intervention and not external factors, before implementing the intervention in a clinical setting. Ideally, similar results would be found for families where a parent died of causes other than cancer. Additionally, more resources will need to be allocated to health care settings in order to ensure the Grief and Communication Family Support Intervention can be implemented and delivered properly.
Sammanfattning

förbättra familjens kommunikation och relationer. Detta innebär att det är möjligt att stödja familjer att hitta sätt att hantera komplexa förändringar i vardagen, och att anpassa sig efter en förälders död, eventuellt genom the Grief and Communication Family Support Intervention. Dock krävs flera studier som testar the Grief and Communication Family Support Intervention i en mer omfattande grupp och med en randomiserad design, för att bekräfta dessa rön.
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Papers
Communication in families with minor children following the loss of a parent to cancer

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\textbf{ABSTRACT}

\textbf{Purpose:} Family communication is a known protective factor for minor children’s psychological health following the death of a parent, but there is little research describing communication within such families specifically from the perspective of the children. The purpose of this study was therefore to explore communication in parentally bereaved families from the perspective of the children and surviving parent.

\textbf{Methods:} Interviews with four parents and four children from four families were analyzed using inductive content analysis. Interviews took place in the family’s home or at the research center based on the family’s wishes 4–14 months after a parent had died. Interviews had an open approach and were based on an interview guide. Each interview was between 60 and 120 min long.

\textbf{Results:} Four categories emerged which were related to family members’ experiences of family communication while adjusting to their new circumstances as bereaved: the importance of open and honest communication in the family; new challenges in the family which affect communication; communicating the need for help; and talking about and remembering the deceased parent.

\textbf{Conclusions:} This study illuminates the connection between family communication and adjustments to new circumstances following the death of a parent. The results suggest that the relationship between family adjustment and communication may be circular whereby the family’s ability to adjust to their new circumstances is affected by how the family communicates. Similarly, family communication may be affected by the family’s coping strategies and ability to adjust to their new circumstances.

\section{1. Introduction}

The death of a parent is among the most traumatic events that a child can experience (Breslau et al., 2004). Loss of a parent is connected to increased vulnerability to psychological problems such as reduced self-esteem and self-confidence, difficulties with communication, school and behavioral problems, and complicated grief (Pfeffer et al., 2000). According to Shapiro et al. (2014) the availability of a warm, positive, affectionate caregiver helps to reduce and regulate negative emotions and re-establish normal routines which helps children to feel safer sharing and exploring grief-related emotions and experiences (Field et al., 2014; Shapiro et al., 2014). However, Kwok et al. (2005) found that stress, including psychological distress, following the death of a spouse may interfere with a parent’s ability to provide positive parenting which is a known protective factor for parentally bereaved children (Sandler et al., 2003).

Many aspects of positive parenting, such as forming an emotional connection, setting boundaries, and showing warmth or affection, involve the use of communication (Ochs and Kremer-Sadlik, 2015). Communication is an important human behavior wherein a people put conscious effort into exchanging information verbally or non-verbally with each other (Miller, 1966; Stacks et al., 2011). When parent-child communication is more open, family relationships tend to be closer (Ochs and Kremer-Sadlik, 2015; Ponnet et al., 2013). Furthermore, verbal and nonverbal family communication facilitates the process of establishing and developing family relationships which increases trust and intimacy within the family (Ochs and Kremer-Sadlik, 2015). Communication is therefore considered one of the most important variables in adjustment following the loss of a loved one (Kamm and Vandenberg, 2001).

Bereaved children are more likely to adjust positively to the loss of a parent if the family shares thoughts and emotions openly (Howell et al.,...
Families who communicate openly about illness and express their emotions tend to have lower levels of depression and anxiety (Howell et al., 2015; Karlsson et al., 2013; Ponnet et al., 2013; Shapiro et al., 2014). Sveen, Kreicbergs, Melcher, and Alvariza (2015) found that teenagers who talked and grieved together with the surviving parent seemed to cope better after the loss than teenagers who did not.

Parentally bereaved families often struggle with open communication, even when the parent is aware that he/she should be modeling open communication for the children (Saldinger et al., 2004). Families sometimes develop spoken or unspoken rules regarding how often and when they may talk about the deceased parent, for fear that the surviving parent will be overwhelmed by grief and unable to cope (Ellis et al., 2013).

There is a great deal of previous research on coping and adjustment following bereavement and communication is an important part of both coping and adjustment. Furthermore, the importance of open communication for parentally bereaved families has been widely acknowledged as it aids both the surviving parent and child in coping with their grief and adjusting to their loss (Kamm and Vandenbergh, 2001; Saldinger et al., 2004; Sandler et al., 2003; Shapiro et al., 2014; Silverman and Worden, 1992; Sveen et al., 2015). Despite this, there is a lack of descriptive studies specifically focused on how bereaved families communicate, how a family's ability to communicate affects or is affected by bereavement, and the child's own experiences of communication and bereavement. By learning more about family experiences from the child's perspective, we may be better able to help these children cope with their loss. This study therefore aims to explore and describe both child and parent experiences of family communication in the first 14 months following a parent's death to cancer.

2. Methods

2.1. Design

This study used a qualitative approach with a descriptive and interpretive design which allows for nuanced descriptions that can provide new information or details. Qualitative methods are often a flexible way of capturing verbatim information and observed behavior (Brink and Wood, 1998). Qualitative methodology focuses on both depth and detail and typically produces detailed information about a small number of persons or cases thereby increasing the depth of understanding for the studied phenomenon. Interviews were used as a way to capture participants’ unique experiences from their own perspective, using their own words (Patton, 2002).

2.2. Procedure

The study was approved by the Regional Ethics Committee 2016/1192-31/1. A letter with information about the study and request for permission to recruit family members of deceased patients was sent to healthcare facility managers at two urban palliative care units in Sweden. After permission was obtained, nurses and counselors at the two units identified eligible families using patient medical records. Eligible families received an information letter from the research group by post, followed by a phone call from one of the researchers one week later, at which time the parent gave verbal consent or declined participation.

Written informed consent was obtained from all participants prior to each interview. Minor children received age-appropriate written and verbal information regarding the study, and gave verbal informed assent.

2.3. Participants

Participants were recruited from two palliative care centers using convenience sampling. Inclusion criteria were families with children aged three and older who had lost a parent to cancer within the past three years. Nineteen families meeting the inclusion criteria were identified. All the families who wished to participate did. Four families including four parents and four children participated in a total of eight interviews (Fig. 1).

2.4. Data collection

Open interviews were conducted based on an interview guide (Table 1) with four parents. The interview guides were created based on questions to parents during the first interview.

<table>
<thead>
<tr>
<th>Question</th>
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<td>Can you tell me how it has been for you to lose your partner?</td>
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<tr>
<td>How have you and your children been doing since the loss?</td>
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<td>How are you and your children doing now?</td>
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<td>How was it right after your partner died?</td>
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<td>How do you feel that communication and relationships are between you and your children?</td>
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<td>How and how often do you talk about your feelings?</td>
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<td>What happens when someone in your family gets upset or sad?</td>
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<td>Do you feel that you are arguing too much with in your family?</td>
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<td>What are the main differences from before your partner died or got sick?</td>
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<td>How do you experience your parenting?</td>
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<td>What consequences of the loss (positive or negative) have occurred?</td>
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Fig. 1. Family members who participated in the interviews.
previous research and clinical experience of all four authors working with bereaved families. Children had been invited to participate in these interviews but parents chose to participate without their children. These interviews provided a context for each family’s unique situation, lasted 60-90 min, and was recorded. Interviews took place at the research center per the parents’ requests. Parents were open and engaged, often becoming emotional and crying as they shared their experience, talked about their deceased spouse, and explained how their children had been affected by their parent’s illness and death. They seemed happy to have someone listen to their experience and relieved to be met with acceptance and understanding.

Follow-up interviews were conducted 2–5 months later to gain a deeper understanding of families’ experiences and communication at which time parents felt comfortable with children participating. Children from three of the four families participated in interviews which were 60–120 min long and focused on how the surviving family members communicate with each other (Table 2). Interviews including minor children took place in the family’s home with the parent present. Children were very open and engaged in the interview process, they answered and asked questions while playing with their pets. Sometimes they got up to wander around and think of an answer or avoid listening to a sibling but mostly they sat next to their parent and were attentive. They shared pictures and toys with the interviewer which reminded them of their deceased parent as well as drawings they had made for their surviving parent or sibling to show their love and make their family member happy. Parents encouraged their children to share and participated by modeling an open attitude and behavior. They did not answer questions until their child had answered and if the child was reluctant to share they prompted the child by reminding them of a specific anecdote or incident they could share with the interviewer. Parents’ answers complemented or clarified children’s answers by providing factual information or context.

The interviewer strived for openness in eliciting each participant's unique experiences. Questions were modified to be age appropriate and were followed up with probing questions to clarify and gain a deeper understanding. Participants were told they could skip questions if they did not want to answer or if the question was upsetting.

### 2.5. Analysis

The first interviews were analyzed using inductive qualitative content analysis (Elo and Kyngäs, 2008). Open coding was conducted while reading each interview 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. This preliminary analysis identified several categories including support which the family had received, coping with the loss, and communication. The category of communication included two subcategories, communication with healthcare professionals and communication within the family. Family communication was chosen as the most pertinent category and the interview guide for the repeated interviews was developed. The repeated interviews were then conducted, transcribed and all eight interviews were analyzed together as described above.

All authors were involved in the analysis. Similarities and differences between the families and within each family were discussed. Categories were adjusted until the authors reached agreement that they were clear and concise enough to describe family communication following the death of a parent. Categories were discussed and compared to eliminate overlapping categories until consensus was reached. The authors have strived to reveal nuanced variation of family experiences of communication. The analysis was further validated during a seminar where data, subcategories, and categories were presented to and discussed with external researchers.

### 3. Results

Four categories related to family members’ experiences of family communication while adjusting to their new circumstances emerged. These categories were: the importance of open and honest communication in the family; new challenges in the family that affect communication; communicating the need for help; and talking about and remembering the deceased parent.

#### 3.1. The importance of open and honest communication in the family

All parents stated that they had always done their best to have open and honest communication within the family and expressed that communication became even more important to them after their partner’s death. This included talking about what the children had done at school, expressing emotions, and talking about their interests or the future. As the father from family 1 put it: “For me, it’s important that we talk and that we are brave enough to share.” He also stated, “We sit and talk more now even if I sometimes don’t have the energy for it because I’m tired.” During both interviews, he spoke about the importance of finding the right time to talk and being transparent about his emotions. The mother from family 4 also emphasized these points and said that telling the children if she was tired or stressed made communication easier which resulted in less conflict between family members.

Parents and children stated that the loss of a parent made it even more important to try to express and understand feelings, provide comfort and support, and show appreciation to each other through verbal and non-verbal communication. The nine-year-old daughter from family 2 describes how she tries to do this: “On Valentine’s Day, right after school on my way home I stopped at the store with a friend and bought some presents … for mom and for my sister … because it was Valentine’s day and I wanted to show that I love them.” All the children shared similar examples of buying presents or drawing pictures for their parent and sibling, in attempts to express love or cheer someone up.
The children shared several of these pictures with the interviewer. The parents gave examples using verbal expression of emotions or appreciation such as telling the children specifically what they had done well instead of simply saying “good job”.

3.2. New challenges in the family that affect communication

The parents struggled to apportion their time between their children following their partner’s death, which according to participants, resulted in more arguments or misunderstandings than before the parent’s death. The younger children often expected to have their parent’s undivided attention and sometimes interpreted a lack of attention as a non-verbal signal that they were not as important as their sibling. During the second interview with family 3, the six-year-old daughter explained: “We usually argue about which one of us gets to hold mom’s hand.” Her mother stated that the girls usually behave in ways that indicate that they are competing for her attention, as a direct effect of having only one parent. Both daughters confirmed that this was true.

Competition between siblings for the surviving parent’s attention seemed closely related to the surviving parent’s struggle to arrange one-on-one time with their child. Parents and children ages 6–9 years, stated that they appreciated one-on-one time because it gave children an opportunity to talk to their parent about their own needs and interests while allowing the parent to give the individual child their undivided attention. Parents stated that they often struggled to arrange this due to scheduling conflicts or difficulty arranging care for the other child, which had not been as much of a challenge while the other parent was alive. The mother from family 3 talked about this during her first interview: “One of us could sit and do something with one of them and the other could sit with the other and build with Legos, they don’t get that now in the same way. I have to plan to … so that one of them is at a friend’s house and I can be with the other one.”

Both daughters from family 3 gave examples of this struggle when asked how things have been since their father died. The six-year-old explained that before he died, each parent would tuck in one of the children at bedtime. For her, one of the biggest changes in her daily life was that she now had to wait longer to get tucked in. This new family circumstance seemed to frustrate both children, but they each also said they understood how challenging it must be for their mother. This was not an issue for family 4 as the 18-year-old son was trying to establish his autonomy from his mother.

The parents talked about feeling that they needed to take on the roles once filled by their deceased partner. Frequently one parent had been responsible for discipline and the other had taken responsibility for the children’s emotional needs. The mother from family 4 described how this led to arguments between her and her 18-year-old son, who had started skipping school following his father’s death: “[His father] was the one who was strict about school. I work so much you know so it has upset while grocery shopping as he had been reminded of his deceased mother. The father had to instantly choose whether or not to encourage his son to share his emotions, and decided that a crowded grocery store may not be the best place for such an emotional discussion. He instead neutralized the situation and brought it up once they were home and could adequately address the child’s feelings.

Children and parents frequently shared memories of the deceased parent, re-telling anecdotes, pointing out things in their daily life that be/she would have liked, or highlighting similarities between the child and the deceased parent. The mother from family 3 describes this in her first interview: “They do things and I say, ‘Your father did that too!’ ‘You are so much like your father in that way.’ I want to talk a lot about him and I know they feel secure with that.”

The younger children talked about what their deceased parent might be doing now, thus making him/her a part of their daily life. The mother from family 3 gave an example of how her daughter would do this during her first interview: “She drew a picture the other day with butterflies and said that her dad is now a soccer coach in butterfly land.”

In this example, the daughter used non-verbal communication, drawing a picture, to express a thought about her deceased father and her need to make sense of his father’s death which led to a verbal dialogue with her mother.

According to children and parents, the children tried to talk or think only about happy memories and avoided talking about sad or scary memories which increased their sadness and distress. In the second interview, the father from family 1 explained: “We talk a little but not with so many details … maybe because they don’t want to be reminded of everything, all of the difficult things they went through.” He also believed that his children were actively avoiding talking about their mother because it made them sad. How much the children spoke about their deceased parent differed in every family, but all the children focused on – or even exaggerated – their positive memories.

Most of the children stated that they had felt more comfortable speaking about feelings with the deceased parent than the surviving one. The 18-year-old son from family 4 talked about how he would always go to his father for support: “I would say that I absolutely miss my social network of extended family, friends, or colleagues to manage day-to-day tasks and maintain effective communication with their children.

Parents also talked about the children taking more responsibility around the house or helping to care for younger sibling. The children understood that their individual and family needs could not be met in the same way as prior to their parent’s death. The father from family 1 stated: “He tries to help a lot with his little brother, but I have talked to him and said, ‘When I am home, I will take care of him. If I’m not home then it’s you.’” The mother from family 2 described that her children now helped with chores more than they had before their father died and that her 16-year-old daughter who chose not to participate in an interview, often took care of her 9-year-old sister by preparing meals and helping with homework, especially when their mother was working.

3.4. Talking about and remembering the deceased parent

According to parents, their children talked about the deceased parent when something triggered thoughts about him/her, for example something that reminded them of a specific incident or seeing a place they had once visited with the deceased parent. Once the child began speaking about their deceased parent, the surviving parent could seize the opportunity and encourage the child to continue talking about – and thus process – their feelings surrounding the death. The parent could also choose to let the child say what he/she wanted to say without encouraging expression of deeper emotions. The father from family 1 described in the second interview: “There needs to be something that triggers their need to talk about their mom but, yeah, and sometimes you find the red button that you can push, but sometimes, no you have to let it go.” A specific example he gave was when one of his children had become upset while grocery shopping as he had been reminded of his deceased mother. The father had to instantaneously choose whether or not to encourage his son to share his emotions, and decided that a crowded grocery store may not be the best place for such an emotional discussion. He instead neutralized the situation and brought it up once they were home and could adequately address the child’s feelings.

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father's role in the family. He was pretty much the only person I talked to.”

When asked how it felt to talk about the deceased parent, participants gave a variety of answers. The nine-year-old daughter from family 2 stated: “It's just like talking about a regular person really.” The 18-year-old son from family 4 said: “I feel a lot better now ... I don't think about it very often, I don't get really sad, it's more like an experience in my life than anything else.” The six-year-old daughter from family 3 looked happy and was laughing as she shared stories about her deceased father. When asked if she usually felt happy when she spoke about him she replied: “Sometimes ... sometimes it makes me sad and sometimes happy ... mostly sad” at which point she began to cry. Her eight-year-old sister stated that she could feel happy or sad, sometimes both simultaneously.

4. Discussion

This study of parentally bereaved families revealed that family communication was affected by new challenges after the loss and the need to adjust to life without the deceased parent. Furthermore, the family's ability to cope with the loss and make necessary adjustments may be affected by their communication. The interviews showed that parents need for help had to be communicated to their social network to prevent them from being overwhelmed by day-to-day tasks that might impede effective communication within the family. Feelings of guilt and shame sometimes hindered this process as parents adjusted to their new identity as a single parent. Older siblings tried to take on more responsibility as they saw their parent struggling in their new role as a single parent whereas younger children found it difficult to balance their cognitive understanding of the difficult situation their parent was now in with their emotional need for attention. Children's differing developmental levels influenced their ability to communicate as well as their communication needs. Importantly, both children and parents frequently shared memories of the deceased parent, but children tried to talk only about happy memories and may have avoided negative memories.

Like many single parents, the parents in this study found parenting challenging as they had to spontaneously take on new roles and responsibilities within the family while providing their children with practical and emotional support, setting boundaries, and managing their own grief. The parents felt uncomfortable in some of these new roles or uncertain how best to perform them. The constellation of roles in family life prior to the parent's illness and death have significant implications for how the family grieves, how they understand and process the loss, and how they adjust to their new life circumstances (Werner-Lin and Blank, 2012). In less functional families, death may leave certain roles vacant and individuals will assign themselves those roles or be assigned them by the other members (Lambert and Detmer, 1993). When compounded by the child's adjustment to new or different parenting strategies, this often led to more conflict within the family. According to Saldinger et al. (2004), spousal loss forces the surviving parent to make many adjustments in family life with parenting being the most complex of these adjustments, because physical exhaustion, grief, sadness, and anger may limit the parent's patience and emotional availability, which in turn limits their ability to maintain open communication with the child (Werner-Lin and Blank, 2012).

The parents in our study had to manage day-to-day tasks and caregiving responsibilities and needed to learn to ask for help from their social network. According to the parents, practical support from the family's social network helped alleviate the parent's stress thereby easing tension in the family. This is in line with earlier research showing that multiple stressors place extra demands on the surviving parent and may leave him/her with less time and energy to care for the child (Salloum et al., 2015; Wolchik et al., 2006) as well as evidence showing that parenting stress was associated with less openness in parent-child communication in both mothers and fathers (Ponnet et al., 2013).

The children in our study were willing and able to talk about happy memories associated with their deceased parent and shared many anecdotes during the interviews which confirms the findings of Silverman and Worden (1992), that bereaved children often reminisced about things they had done with the deceased parent. Reminiscing about emotional experiences provides an opportunity for reflection and re-evaluation of the experience; this facilitates processing emotions, consolidating self-concept, and gaining insight into others' and one's own feelings, all of which teach children to regulate their emotions and respond to others in socially competent ways (Quas and Fivush, 2009; Salmon and Reese, 2016; van Bergen and Salmon, 2010).

According to parents, the children in our study were avoiding sad and scary memories associated with their deceased parent. This type of thought avoidance can hinder the child's grieving process, and somatic and psychological symptoms can develop if children do not acknowledge or experience the emotions surrounding their loss (Howell et al., 2016; Worden, 1996). Furthermore, talking about their parent's death can help children process the loss emotionally and cognitively, which can lead to more adaptive grief and higher self-esteem (Fearnley, 2015; Field et al., 2014; Howell et al., 2015; Quas and Fivush, 2009).

Most of the children said their deceased parent was the one they had felt closest to. This may be due to recall bias as the children focused on positive memories and avoided negative memories associated with their deceased parent. These responses were collected retrospectively which calls into question the validity of the data and accuracy of children's memories (Worden, 1996).

4.1. Methodological considerations

Strengths of this study include speaking directly with the children which made it possible to present more child-centered results and a more complete picture of family communication and bereavement. The use of follow-up interviews allowed us to gain a deeper understanding of family experiences. This also built trust, so most parents agreed to let their children participate in the second interview. This allowed us to examine both the children's and parents' sometimes conflicting perspectives, and receive participant feedback (Creswell and Poth, 2017). As all interviews were conducted within the first 14 months following the parent's death, our results offer a deeper understanding of family communication in the early stages of bereavement. As bereaved families are in a vulnerable situation, the interviews were conducted by the first author who has several years of experience working with children and families as a mental-health counselor. This experience helped to create a warm and safe atmosphere for children and parents.

The main limitation of this study was that we interviewed a small, specifically selected sample of families who had received palliative care which strives to meet the social, psychological, and spiritual needs of both patients and family members (Kellehear, 1999; Sawatzky et al., 2016). Thus, our findings may not be transferable to families from other healthcare settings or families in small towns or other cultures. Furthermore, differences between the families including but not limited to, level of family functioning, cultural background, parent gender, and child age may have affected or influenced what information was shared during the interviews, emerging themes, and our resulting categories.

Reasons for declining to participate included lack of energy and reluctance to re-awaken negative feelings. This may indicate that our sample is biased towards participants who were better able to cope with their bereavement (Stroebel and Stroebel, 1989). More research is needed. Purposive sampling in terms of children's development stage would provide more knowledge.

4.2. Clinical implications

The results of this study can help clinicians to identify strategies which can be taught in a clinical setting such as sharing feelings. By understanding how the surviving parent's identity or sense of autonomy is affected by bereavement, clinicians will be able to normalize this
experience and help the parent to manage feelings of guilt or shame that may be associated with this change in identity. Parents need support in dealing with feelings of guilt and shame and may benefit from learning time management and stress reduction techniques. Clinicians can provide validation or normalization while encouraging parents to ask for help from their social network. Furthermore, the results can aid clinicians in helping families to problem solve or resolve family conflict. The results may serve as a guide for clinicians in starting a dialogue with bereaved children as it may be more effective for clinicians to start this dialogue by encouraging children to focus on happy memories or anecdotes which the child feels comfortable with and gradually moving towards sad or scary memories which the child may be avoiding.

5. Conclusions

This study illuminates the connection between family communication and adjustment to new circumstances following the death of a parent by providing a contextualized understanding of family communication in parentally bereaved families. Parents struggled with their own identity and feelings of guilt or shame which in turn affected their ability to communicate with their children and support network. Adjustment to new parenting roles often lead to increased family conflict. Parents expressed that they were under a lot of stress and needed encouragement and validation in asking for help from their social network.

The relationship between family adjustment and communication may be circular whereby the family’s ability to adjust to their new circumstances is affected by how the family communicates. Similarly, family communication may be affected by the family’s coping strategies and ability to adjust to their new circumstances.

Reminiscing about the deceased parent may aid children in processing their emotions surrounding their parent’s death and avoiding sad or scary memories may lead to the development of somatic or psychological problems. This may be evidence of a link between family communication and psychological health and warrants further exploration in future studies.

Declarations of interest

None declared.

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References


Family Communication and Psychological Health in Children and Adolescents Following a Parent’s Death From Cancer

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Abstract
Parentally bereaved children and adolescents are at risk of developing psychological health problems. Evidence for a correlation between communication and broad measures of psychological health exists in other populations. The aim of this study was to examine associations between family communication and specific aspects of psychological health for children and adolescents following a parent’s death from cancer using parent-proxy and adolescent self-reports. Parent-proxy reports for children and adolescents, and adolescent self-reports for Parent–Adolescent Communication, Strengths and Difficulties Questionnaire, and Prolonged Grief-13 child were analyzed using descriptive statistics and Spearman’s correlation. Parents rated communication as moderate in quality and reported good psychological health for children and adolescents. Adolescent self-reports indicated low-quality communication with their parent and poor psychological health. Significant associations between Parent–Adolescent Communication subscales and Strengths and

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Difficulties Questionnaire subscales were found for each group. Prolonged grief was associated with emotional problems but not communication for all three groups.

**Keywords**  
childhood bereavement, family communication, internalizing problems, externalizing problems, prolonged grief

**Introduction**  
Children and adolescents are at risk of developing increased internalizing problems such as depression, anxiety, somatic complaints, emotional problems, or difficulty forming relationships with peers; externalizing problems such as aggression, delinquency hyperactivity, and conduct disorder; as well as prolonged grief following the death of a parent (Ayers et al., 2014; Dowdney, 2000; Spuij, Dekovic, & Boelen, 2015; Stikkelbroek, Bodden, Reitz, Vollebergh, & van Baar, 2016). For example, Stikkelbroek et al. (2016) found that adolescents were significantly more likely to develop or have increased internalizing problems within 2 years of a family member’s death compared with nonbereaved controls while accounting for preloss internalizing problems. This was not found for externalizing problems. However, the study included all types of family bereavement and was not specifically focused on parental bereavement which is often considered more traumatic for the child as they are permanently losing a primary attachment figure (Dowdney, 2000; Howell, Shapiro, Layne, & Kaplow, 2015).

Prolonged grief disorder, a type of complicated grief (Cohen & Mannarino, 2004; Spuij, van Londen-Huiberts, & Boelen, 2013), is characterized as a sense of disbelief that the death happened, feelings of anger, guilt or bitterness, prolonged intense yearning, intense painful emotions, rumination, catastrophizing, and avoidance of reminders of the loss (Shear, 2012; Shear & Shair, 2005; Spuij et al., 2015). Prolonged grief disorder in children and adolescents has been associated with increased suicidal ideation and impairments in health and quality of life (Spuij et al., 2013).

Clinical case studies indicate that child and adolescent grief reactions differ based on the child’s age and development, but research has not yet established specific guidelines regarding differential disturbance in bereaved children and adolescents (Dowdney, 2000). Knowledge of stages of child and adolescent development along with clinical case studies may provide a foundation for understanding children’s varied responses to loss (Dowdney, 2000; Green & Connolly, 2009). It is important to keep in mind that children’s cognitive understanding or interpretation of death may not match their level of development or
maturity in other areas and may differ based on life experiences associated with death and loss; therefore, both age and development must be considered.

Generally, children’s grief may appear sporadic and short lived, but their limited language skills may be masking the actual duration and intensity of their grief. Children’s grief reactions differ from adult grief reactions in that children may have a limited capacity to tolerate emotional pain; children may be more sensitive to being different or perceived as different from their peers; and some children are unable to understand the implications of death such as irreversibility, universality, and inevitability (Green & Connolly, 2009).

Children under the age of 5 years know that death exists but struggle to understand that it is final. They often ask questions about when the dead person will return and may believe that their family and friends cannot die. They need continuous reassurance about the well-being of the people closest to them. Young children typically react strongly to significant loss, even if they cannot express it in words. Children aged 5 to 10 years begin to grasp the finality and universality of death (Pettle & Britten, 1995). Disturbances in mood such as jealousy, clinginess, aggression, anxiety, irritability, impatience, and even dysphoria are common (Dowdney, 2000). Adolescents have developed advanced cognitive skills which cause them to be more critical of information and explanations given by adults and may begin to develop their own beliefs and ideas about death that contradict with their parents/caregivers (Pettle & Britten, 1995).

A known protective factor for children and adolescent’s psychological health following the death of a parent is parent–child communication (Howell et al., 2016; Shapiro, Howell, & Kaplow, 2014). Communication is the primary process by which children and adolescents receive information and socioemotional support (Houck, Rodrigue, & Lobato, 2007). Furthermore, aspects of family communication such as exchange of positives, listening, and expression skills are important aspects of positive parenting which can reduce mental health problems for children independent of the impact of negative life events (Haine, Wolchik, Sandler, Millsap, & Ayers, 2006). The child’s age and developmental level help to determine how parents and children communicate with each other. Furthermore, communication within the family may be affected by new challenges which arise following a parent’s death and the family’s ability to cope with the loss (Weber, Alvariza, Kreicbergs, & Sveen, 2019).

Evidence for a correlation between communication and psychological health exists in several populations other than bereaved children and adolescents, but these studies often rely on broad measures of psychological health or examine only one specific psychological disorder (Heidari, Mortezaee, Masomi, & Raji, 2016; Hollmann, Gorges, & Wild, 2016; Houck et al., 2007; Wilson, Chernichky, Wilkum, & Owlett, 2014).

Even though communication is known to be a protective factor following the death of a parent, there is still a need to better understand which aspects of
psychological health are associated with communication in order to develop psychosocial interventions targeting the most relevant problems for parentally bereaved children and adolescents. Furthermore, to our knowledge, there are no studies examining the relation between family communication and psychological health in children and adolescents following a parent’s death from cancer which use both parent reports and adolescent self-reports. The aim of this study was therefore to use both parent and adolescent reports to examine the relationship between family communication and specific aspects of psychological health of children and adolescents including emotional problems, conduct problems, prosocial behavior, hyperactivity, relationship problems, and prolonged grief following a parent’s death from cancer.

Methods

Participants

Individuals who died of cancer between 2013 and 2015 and were aged between 25 and 65 years at the time of death were identified by the Swedish National Causes of Death Register. The deceased were linked to offspring by the Multi-Generational Register at Statistics Sweden to identify if he or she was a parent of a child or children aged between 1 and 18 years at the time of death. If the deceased had been living in Stockholm County with a partner, the family was eligible for the study. The participants are the surviving partner and children. Participants must reside in Stockholm County during data collection and speak and understand written and spoken Swedish. Specific inclusion criteria from the National Board of Health and Welfare included: The deceased parent and surviving parent must have lived at the same address and children and adolescents must be registered at the same address as their parent at the time of the study. This effectively excludes families with separated or divorced parents and adolescents who have moved from the family home.

In total, 214 eligible families were identified and 49 families consented to participation. Parents ($n = 39$), with a mean age of 48.90 years ($SD = 6.07$), filled in parent report questionnaires for a total of 55 children, where 25 were girls and 30 were boys. Children’s mean age was 12.78 years ($SD = 4.42$). Fourteen of the participating parents filled in questionnaires for more than one child. Adolescent self-reports were collected from 23 adolescents aged 12 to 20 years, where 15 were girls and 8 were boys, with a mean age of 16.2 years ($SD = 1.88$) some adolescents participated even though their parent did not.

According to parent-proxy reports, none of the children or adolescents had sought professional help for psychological health before their parent became ill. Adolescent self-reports indicated that one adolescent had sought professional help for psychological health prior to their parent’s illness. Mean time since loss
for parent reports was 2.78 years ($SD = 0.78$) and 2.9 years ($SD = 0.91$) for adolescent self-reports.

**Procedure**

The study was approved by the Regional Ethics Committee 2016/1192–31/1. Special consideration was taken with regard to the ethical aspects of this study because children and adolescents were involved and the harm a project inflicts must be balanced against the scientific knowledge it produces. Surviving parents identified as potential participants were sent information about the study by Statistics Sweden. The information letter included brief information about the study, a link to the questionnaire website where they could sign up for the study, and contact information for the research group. If families chose to participate, parents went online to the website, provided their contact information, indicated how many children they had in each age-group, and marked that they gave informed consent for their own and their children’s participation. Adolescents aged 15 years and older were able to give consent for participation even if their parent did not, and all children were required to assent to participation in accordance with Swedish law. If families preferred to participate using a paper questionnaire, they could request paper questionnaires from the research team. As the informational letters were sent out by Statistics Sweden, the research group did not have access to the families’ contact information and were therefore unable to contact potential participants unless they signed up for the study.

A link to the relevant questionnaires based on children’s age was then sent to parent’s e-mail address. Parents were asked to fill in a parent report questionnaire for each of their children regardless of the child’s age. Adolescents aged 12 years or older received a separate adolescent questionnaire once the surviving parent and the adolescent gave consent. If the participants did not fill in the questionnaire within 2 weeks, a reminder e-mail was sent.

**Measurements**

**Demographic variables.** Demographic questions were included in the parent and adolescent questionnaires and included participants’ age and gender: Time since the parent’s death, and the surviving parent’s employment and marital status were included in the parent version.

**Parent and adolescent communication.** The Parent and Adolescent Communication (PAC) Scale consists of 20 items, comprised of a parent form which was included in the parent questionnaire and an adolescent form included in the adolescent questionnaire. It measures family communication on two subscales: Open Family Communication and Problems in Family Communication with each subscale consisting of 10 items. Open communication reflects responses related to free expression and understanding, whereas problem communication
measures hesitancy to disclose concerns and negative interaction patterns. Higher scores on the Open Communication subscale indicate higher levels of open communication. The scores for the Problem Communication subscale are reversed so higher scores indicate less problem communication. The two subscales are added together to get a total score for parent–adolescent communication with higher scores indicating a better quality of communication (Barnes & Olson, 1985, 2003). Scores below 70 indicate low communication and is used as the cutoff score in this study. The PAC has been validated using factor analysis (Barnes & Olson, 1985). The PAC was forward translated from English to Swedish by two independent researchers and back-translated to English by a native English speaker. The questions were then validated face to face with parents, children, and adolescents who participated in an earlier study, and families in the research group’s professional network. Internal consistency for the parent reports for children in this study was found to be high, \( \alpha = .76 \) for the Open Communication subscale, \( \alpha = .73 \) for the Problem Communication subscale.

For the parent reports for adolescents, internal consistency was high with \( \alpha = .71 \) for the Open Communication subscale and \( \alpha = .71 \) for the Problem Communication subscale.

For the adolescent self-reports, \( \alpha = .89 \) for the Open Communication subscale and \( \alpha = .84 \) for the Problem Communication subscale. While this scale was developed using age-appropriate language so that it could be completed by adolescents aged 12 years and older, we have chosen to use parent-proxy reports for children under the age of 12 years, as the only known reason for the age limit for the scale is children’s reading level. This decision made it possible to assess how parents communicate with younger children and adolescents.

**Prolonged grief.** The Prolonged Grief Disorder-13 Child (PG-13 Child) was completed by parents and adolescents to assess prolonged grief. The PG-13 Child is based on the PG-13 for adults (Pohlkamp, Kreicbergs, Prigerson, & Sveen, 2018; Prigerson et al., 2009) and is comprised of 13 items including 2 on duration and impairment which are answered with yes or no and 11 items assessing cognitive, behavioral, and emotional symptoms related to grief. Items 1, 2, 4, and 5 are rated on a 5-point scale measuring frequency with answers ranging from not at all to several times a day. Items 6 to 12 measure intensity of symptoms from not at all to overwhelming. The PG-13 total score is used in this study which is a continuous measure calculated by summing the symptom items, with scores ranging from 11 to 55. The Swedish version of PG-13 Child and the parent report version have previously been translated by the National Centre of Disaster Psychiatry at Uppsala University in 2017. Internal consistency for the PG-13 parent report for children was high with \( \alpha = .88 \), and for parent reports regarding adolescents, \( \alpha = .92 \). For the adolescent self-report, \( \alpha = .82 \).
Strengths and difficulties. Parents completed the parent report and adolescents completed the self-report of the Strengths and Difficulties Questionnaire (SDQ). The SDQ is comprised of 25 questions which are divided into five subscales: Emotional Symptoms, Conduct Problems, Hyperactivity, Peer Relationship Problems, and Prosocial Behavior. These subscales can be combined to produce a score for internalizing problems, externalizing problems, and total difficulties. Each item is scored on a scale of 0 to 2 with 0 indicating not true, 1 indicating somewhat true, and 2 indicating certainly true. Questions 7, 11, 14, 21, and 25 are reverse scored. Higher scores indicate more problems. Cutoff scores for each subscale were defined based on a population-based study in the United Kingdom such that 80% of children’s scores were categorized as normal, 10% as borderline, and 10% as abnormal. Validity of the SDQ’s five-factor structure has been supported in large-scale surveys (Goodman, 2001; Malmberg, Rydell, & Smedje, 2003; Smedje, Broman, Hetta, & Von Knorring, 1999). Internal consistency was acceptable for the parent-proxy reports regarding children for total problem score $\alpha = .69$ and parent reports regarding adolescents was high with $\alpha = .80$. Internal consistency was acceptable for the adolescent self-reports with $\alpha = .69$.

Analysis

Descriptive statistics was used to describe demographic variables, family communication, and psychological health. Parent reports were divided into two age groups, children aged 4 to 11 years ($n = 22$) and adolescents ($n = 33$). Spearman correlation coefficients were calculated, along with $p$ values, using cluster robust covariance estimates, taking into account that some parents answered for several children in the case of siblings. The functions rank, lm, cluster-vcov, and coeftest, from packages base, stats, multiwayvcov, and lmtest, in R version 3.5.0 were used. For adolescent self-reports, Spearman correlation coefficients were calculated, along with $p$ values in SPSS version 22. Spearman correlation was chosen due to the small sample size.

Results

Communication and Psychological Health Following a Parent’s Death From Cancer

The PAC total score for parent reports was 75.36 ($SD = 9.36$) for children aged 4 to 11 years and 78.4 ($SD = 9.89$) for adolescents which indicates a moderate level of communication with their child (Table 1). Ten parents (eight mothers and two fathers) rated their communication with their children (four daughters and seven sons) as being low or very low. Of these, six were children and five were adolescents. One of these parents rated their communication with both of their

...
adolescents as low and one parent rated low communication with only one of his or her three adolescents.

Parent ratings of child and adolescent psychological health indicated that most children were within the normal range, with a mean SDQ total difficulties scores of 8.59 (SD = 5.21) for children aged 4 to 11 years and 9.09 (SD = 6.83) for adolescents (Table 1). Seven parents rated their child as being in the abnormal range for total difficulties, four girls and three boys, of which two were children and five were adolescents. According to the parents, children’s symptoms of prolonged grief following a parent’s death from cancer were low, as PG-13 mean total score was 13.9 (SD = 3.71) for children aged 4 to 11 years and 18.41 (SD = 8.08) for adolescents (Table 1).

The adolescents (n = 23) reported low quality of communication with the surviving parent with PAC total score of 63.43 (SD = 6.50). One adolescent who rated communication with his or her parent above the cutoff for low communication had a parent who rated their communication as low (Table 2).

### Table 1. Parent Reports of Psychological Health and Communication.

<table>
<thead>
<tr>
<th></th>
<th>Parent report for children</th>
<th>Parent report for adolescents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Age 4–11</td>
<td>Age 12–20</td>
</tr>
<tr>
<td></td>
<td>(n = 22)</td>
<td>(n = 33)</td>
</tr>
<tr>
<td>PAC total</td>
<td>75.36 9.36 (27%)</td>
<td>78.4 9.89 (15%)</td>
</tr>
<tr>
<td>SDQ Total Problem Score</td>
<td>8.59 5.21 (9%)</td>
<td>9.09 6.83 (15%)</td>
</tr>
<tr>
<td>PG13 total</td>
<td>13.9 3.71 NA</td>
<td>18.41 8.08 NA</td>
</tr>
</tbody>
</table>

Note. PAC = Parent–Adolescent Communication Scale; SDQ = Strengths and Difficulties Questionnaire; PG-13-child = PG-13 Prolonged Grief Disorder-13-child.

### Table 2. Adolescent Reports of Psychological Health and Communication.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Number above/below cutoff (% of sample)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PAC total</td>
<td>63.43</td>
<td>6.50</td>
<td>20 (87%)</td>
</tr>
<tr>
<td>SDQ Total Problem Score</td>
<td>29.21</td>
<td>7.40</td>
<td>22 (95%)</td>
</tr>
<tr>
<td>PG13 total (n = 52)</td>
<td>23.86</td>
<td>7.36</td>
<td>NA</td>
</tr>
</tbody>
</table>

Note. PAC = Parent–Adolescent Communication Scale; SDQ = Strengths and Difficulties Questionnaire; PG-13-child = PG-13 Prolonged Grief Disorder-13-child.
Adolescents reported SDQ Total difficulties mean score of 29.21 ($SD = 7.40$) indicating that 22 adolescents scored in the abnormal range for total difficulties and one scored in the borderline range. These scores imply that all of adolescents in our sample may be experiencing some type of clinically significant psychological distress. The adolescent mean scores for PG-13 were 23.86 ($SD = 7.36$; Table 2).

**Correlations Between Communication Psychological Health Following a Parent’s Death From Cancer**

According to the parent reports, better communication (PAC total) between the parent and child was associated with fewer psychological health problems in children aged 4 to 11 years ($n = 22$) following a parent’s death from cancer. More open communication was associated with fewer conduct problems and less hyperactivity. Furthermore, increased problem communication was associated with increased conduct and emotional problems. There were no significant associations between communication and, peer problems, prosocial behavior or symptoms of prolonged grief (Table 3).

Similarly, parent reports for adolescents ($n = 33$) indicated that better communication (PAC total) between the parent and child was associated with fewer psychological health problems in the children following a parent’s death from cancer. However, for this age-group, open communication was associated with more prosocial behavior and not associated with conduct problems. Similarly, less problem communication was associated with more prosocial behavior. Furthermore, increased problem communication was associated with increased conduct and emotional problems. There were no significant associations between communication and hyperactivity, peer problems, or symptoms of prolonged grief (Table 3).

Adolescents’ self-reported psychological health problems were related less open communication with the parent. There were low to moderate correlations between communication and prosocial behavior but these were not statistically significant. Adolescents self-reported conduct problems were associated with lower quality of parent–adolescent communication (PAC total, PAC open, and PAC problem). Unlike in the parent report, there was no association between adolescents’ self-reported emotional problems and quality of communication (Table 4).

**Correlations Between Strength and Difficulties and Prolonged Grief Following a Parent’s Death From Cancer**

For children aged 4 to 11 years, only the Emotional Problems subscale was significantly positively correlated with symptoms of prolonged grief. There were significant correlations between parent-reported prolonged grief symptoms
Table 3. Parent Reports: Spearman Correlation Coefficient ($p$ Value) Between Communication and Psychological Health.

<table>
<thead>
<tr>
<th></th>
<th>Parent report for children</th>
<th></th>
<th>Parent report for adolescents</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Age 4–11 ($n = 22$)</td>
<td></td>
<td>Age 12–20 ($n = 33$)</td>
<td></td>
</tr>
<tr>
<td>PAC Total</td>
<td></td>
<td></td>
<td>PAC Total</td>
<td></td>
</tr>
<tr>
<td>SDQ Total Problem Score</td>
<td>$-0.38 (0.09)$</td>
<td>$-0.28 (0.20)$</td>
<td>$-0.38 (0.07)$</td>
<td>$-0.35 (0.04)$</td>
</tr>
<tr>
<td>SDQ Conduct</td>
<td>$0.13 (0.55)$</td>
<td>$0.15 (0.46)$</td>
<td>$0.19 (0.42)$</td>
<td>$0.45 (0.00)$</td>
</tr>
<tr>
<td>SDQ Hyper-activity</td>
<td>$-0.41 (0.04)$</td>
<td>$-0.27 (0.23)$</td>
<td>$-0.40 (0.04)$</td>
<td>$-0.30 (0.05)$</td>
</tr>
<tr>
<td>SDQ Peer</td>
<td>$-0.56 (0.00)$</td>
<td>$-0.55 (0.00)$</td>
<td>$-0.37 (0.03)$</td>
<td>$-0.43 (0.00)$</td>
</tr>
<tr>
<td>SDQ Emotional</td>
<td>$-0.34 (0.11)$</td>
<td>$-0.43 (0.03)$</td>
<td>$-0.22 (0.35)$</td>
<td>$-0.17 (0.41)$</td>
</tr>
<tr>
<td>SDQ Prosocial</td>
<td>$0.01 (0.94)$</td>
<td>$0.17 (0.41)$</td>
<td>$-0.17 (0.42)$</td>
<td>$-0.16 (0.32)$</td>
</tr>
<tr>
<td>PG13-child total</td>
<td>$-0.07 (0.71)$</td>
<td>$0.04 (0.84)$</td>
<td>$-0.21 (0.29)$</td>
<td>$-0.23 (0.30)$</td>
</tr>
</tbody>
</table>

Note. PAC = Parent–Adolescent Communication Scale; SDQ = Strengths and Difficulties Questionnaire; PG-13-child = PG-13 Prolonged Grief Disorder-13-child.

$p < .05.$
for adolescents and the SDQ total difficulties score as well as the subscale emotional problems (Table 5). Adolescents’ self-reported symptoms of prolonged grief were associated with emotional and conduct problems (Table 5). These scores indicate that children and adolescents with more emotional problems may also be experiencing more symptoms of prolonged grief or that the symptoms of prolonged grief overlap with symptoms related to emotional problems.

**Discussion**

This is the first study, to our knowledge, examining the association between family communication and specific aspects of psychological health in children.
and adolescents following a parent’s death from cancer, using both parent and adolescent reports. Our results showed that many adolescents reported poor psychological health and low or very low quality of parent–child communication. Parents rated their children and adolescents as being in the normal range for psychological health problems and reported moderate communication with both age groups. A significant correlation between communication and conduct problems was found for all three groups. Communication was not associated with symptoms of prolonged grief for any group, but prolonged grief was associated with emotional problems in all three groups.

Parent reports in our study indicated that between 3% and 27% of children and adolescents may have a clinically significant level of psychological symptoms which is in line with statistics cited in previous research (Cipriano & Cipriano, 2017; Howell et al., 2016; Melhem, Porta, Shamseddeen, Walker, Payne, & Brent, 2011; Worden & Silverman, 1996). In this study, adolescent self-reports indicated that this percentage was much higher, with 95% of adolescents reporting scores above the cutoff for SDQ total difficulties. This indicates that the adolescents who participated in our study may be experiencing poor overall psychological health which is in contrast to the findings of Heidari et al. (2016) that only 8% of adolescent self-reports indicated poor psychological health and 48% indicated moderate psychological health. One reason for this may be that cross-cultural studies have shown that Scandinavian parents often report fewer symptoms and Scandinavian adolescents often report more symptoms, than participants from other countries (Broberg et al., 2001; Heyerdahl, Kvernmo, & Wichstrøm, 2004; Rescorla et al., 2007; Van Roy, Groholt, Heyerdahl, & Clench-Aas, 2010). It is also possible that the adolescents exhibiting the most symptoms are those who chose to respond to the questionnaire.

According to parent and adolescent reports, better quality communication was associated with fewer psychological health problems in children and adolescents following a parent’s death from cancer. Specifically, more open communication was associated with better overall psychological health and more problem communication was associated with reduced overall psychological health. This was similar to findings of Houck et al. (2007) that better quality of parent–adolescent communication when a parent was chronically ill was associated with fewer adolescent reports of posttraumatic stress disorder. Howell et al. (2015) found that adolescents with clinically significant psychological health problems were more likely to avoid, suppress, or hide their feelings, in other words not communicate with their parent, whereas adolescents who used expressive coping strategies and were willing to process and openly express difficult emotions displayed more adaptive functioning following their parent’s death.

The significant positive association between parent reports of open communication and prosocial behavior in adolescents and moderate negative association between adolescent self-reports of problem communication and prosocial
behavior indicates that communication may be important for increasing prosocial behavior in adolescents but not children under the age of 12 years. Young (2012) points out that cognitive and psychosocial development occur simultaneously. In other words, as a child’s cognitive skills are developing, so are their social and affective skills, although not necessarily at the same rate. The children in our study, aged 4 to 11 years, are likely able to use inductive reasoning or focus on a multifaceted problem, whereas adolescents are not only capable of these tasks but can also actively choose to engage in them or not. The issue is the adolescent’s disposition or desire to use a skill or execute a task (Kuhn, 2008). This may help to explain why communication was associated with prosocial behavior in adolescents as parents may be able to use communication to convince or encourage adolescents to engage in prosocial behavior thereby changing their disposition. This may not work the same way with younger children who are less skilled at inductive reasoning and problem-solving and less aware of their conscious decisions to engage in or refrain from specific tasks.

Conduct problems were associated with communication for all three groups. Parent reports for children aged 4 to 11 as well as adolescent self-reports showed that increased open communication was associated with fewer conduct problems and decreased open communication is associated with more conduct problems. Openness in communication is often associated with more sharing of information which may reduce the child’s uncertainty and anxiety (Houck et al., 2007). Furthermore, increased problem communication was associated with more conduct problems according to parent reports for both age groups and adolescent self-reports. Houck et al. (2007) found that more problem communication was associated with higher levels of posttraumatic stress and anxiety and that increased conflict may lead to adolescents developing feelings of vulnerability, anxiety, and isolation. For younger children, these conduct problems may appear as age-appropriate behavioral and emotional problems (Dowdney, 2000) such as temper tantrums, irritability, and impatience, whereas adolescents are more likely to exhibit aggression and delinquency (Ayers et al., 2014), concentration and behavioral problems (Bergman, Axberg, & Hanson, 2017; McClatchey & Vonk, 2005), and risk-taking behaviors such as substance abuse, criminal behavior, promiscuity, and reckless driving (Ellis, Dowrick, & Lloyd-Williams, 2013; McClatchey & Vonk, 2005).

Higher levels of problem communication were also associated with more emotional problems according to parent reports for both age groups but not for adolescent self-reports. As the adolescents’ ability to reflect on their own thinking is still developing, and the content and meaning of what the adolescent is thinking about affect the type of thinking that occurs (Kuhn, 2008), they may not be able to accurately separate their behavioral responses into the categories of conduct and emotion. A behavior such as throwing or kicking something out of frustration or yelling at a parent may be attributed by the adolescent to conduct problems as these are behavioral reactions but the parent may interpret
it as an emotional response. Adolescents may not be able to identify and reflect on the emotion that is responsible for the behavioral response and therefore do not answer questions about their worry or fears accurately. Worden (1996) states that children who show more aggression, anger, or acting out behavior during the first 2 years following their parent’s death were more fearful or anxious regarding their surviving parent’s health and safety, were less able or likely to speak about their deceased parent, and had a lower sense of self-efficacy.

The correlation between the scores on PG-13 and SDQ indicates that symptoms of prolonged grief may overlap with symptoms related to emotional or conduct problems. Melhem et al. (2011) found that children with prolonged grief show greater functional impairment within the first 4 years following the death and that the combination of prolonged grief in the child and surviving parent was a reliable predictor of the child developing depression up to 3 years following their parent’s death. Similarly, lifetime comorbidity between prolonged grief and mood or anxiety disorders is a common occurrence in adults (Shear et al., 2011) and this could be assumed to be true for children and adolescents as well.

**Strengths and Limitations**

This study had several strengths and limitations. A strength is including the use of both parent and adolescent reports. Special consideration was taken with regard to the ethical aspects of this study because children and adolescents were involved and the harm a project inflicts must be balanced against the scientific knowledge it produces.

A limitation of this study is the small sample size. While our results had a high level of significance, they may not be generalizable to all children and adolescents who have lost a parent to cancer. Specific guidelines from The National Board of Health and Welfare and Statistics Sweden did affect our ability to recruit participants as families with separated or divorced parents and adolescents who had moved out of the family home were excluded. The rational given for these criteria was that there may be a possibility that the child or adolescent may not have had contact with their deceased parent and therefore not been aware of the deceased parents’ illness or death and that learning such information would possibly be traumatic or harmful to the children.

The fact that the research group could not contact participants during the recruitment process may have also affected the response rate for this study as the participants had to actively contact the research group. The requirement of active participation on the part of participants during the recruitment process may have also led to a more biased sample which included only those families already possessing adequate coping skills and possibly higher levels of psychological health and communication.
A limitation of the study is that we do not have information on the family members' history of psychological health prior to the loss; hence, we do not know if they already had psychological problems. Another limitation is a lack of information regarding additional stressors, such as other losses and financial problems in the family, which may affect the families’ psychological health.

Furthermore, most families in our study seemed to have a high degree of functionality with parents who were educated and working full time. Despite this, our results indicate a high level of psychological health problems. It could be that nonresponders may be less educated, with less resources and coping skills and may have even higher levels of psychological health problems and poor-quality communication.

A methodological consideration for this study was the use of PAC for parents' communication with children under the age of 12 years. The scale was developed to be readable by children as young as 12 years, but information regarding age restrictions for the use of the parent report was not found. The research group decided that, since the age limit seemed to be due to issues of comprehension and readability for the child or adolescent and not the parent, the parent report should be used for both age groups in order to have a consistent measurement for communication for all three groups.

Conclusions and Clinical Implications
An association between family communication and children’s psychological health was found. Our results indicate that focusing on communication between the surviving parent and child may be a useful target of clinical intervention. It can be hypothesized that teaching families to reduce problem communication and increase open communication could lead to increased prosocial behavior and decreased conduct problems in children and adolescents following a parent’s death from cancer. Similarly, interventions targeting specific behaviors such as reinforcing positive behaviors and teaching new skills or coping strategies to replace negative behaviors may in turn lead to improved communication such as a reduction in conflict or arguments. The association between symptoms of prolonged grief and conduct and emotional problems helps to illuminate the many ways in which children and adolescents may express their grief following a parent’s death from cancer which provides useful information for parents, teachers, and clinicians working to meet the psychological and emotional needs of these children and adolescents.

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Positive parenting as a protective resource for parentally bereaved children. Death


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Adaptation of a Grief and Communication Family Support Intervention for Parentally Bereaved Families in Sweden

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Adaptation of a Grief and Communication Family Support Intervention for Parentally Bereaved Families in Sweden

Megan Weber, Anette Alvariza, Ulrika Kreicbergs, and Josefín Sveen

ABSTRACT

This article aims to describe the adaptation of the evidence-based Family Bereavement Program to a Swedish context. Empirical support indicating that family communication is a protective factor for parentally bereaved children was used to motivate the focus of the intervention. Modules from the Family Bereavement Program manual were translated, culturally adapted, and modified to fit a family format. The manual for the Grief and Communication Family Support Intervention was pilot-tested with two families, which resulted in minor modifications being made to the manual. Therapists reported that they could follow the manual and adapt it to children’s varying ages.

Introduction

Parentally bereaved children are vulnerable to psychological and somatic problems which may occur directly following the parent’s death or develop several years later (Ayers et al., 2014; Bergman, Axberg, & Hanson, 2017; Ellis, Dowrick, & Lloyd-Williams, 2013; Pfeffer, Karus, Siegel, & Jiang, 2000; Sandler et al., 1992; Worden, 1996; Worden & Silverman, 1996). The loss of a parent during childhood or adolescence is often a traumatic event and children in this situation typically need a lot of support. However, the remaining parent may be struggling with their own grief and changes in the family situation or family roles following the loss, which can affect their ability to communicate with their children or provide positive and supportive parenting (Weber, Alvariza, Kreicbergs, & Sveen, 2019).

Family communication is a known protective factor for the psychological health of parentally bereaved children (Kamm & Vandenbergh, 2001). Furthermore, aspects of family communication such as sharing feelings, showing appreciation of one another, listening, and expression skills are found to be important aspects of positive and supportive parenting, which is a compensatory protective resource for parentally bereaved children. This means that positive and supportive parenting can potentially reduce mental health problems for children independent of the impact of negative life events (Haine, Wolchik, Sandler, Millsap, & Ayers, 2006). Positive and supportive parenting creates an environment which supports children’s needs, goals, and development, while compensating for negative life events which may threaten achievement of developmental milestones. Modeling of positive behavior may also promote the development of social skills, such as non-aggressive conflict resolution and problem-solving strategies, and other coping skills (Haine et al., 2006). Moreover, supportive parents have been shown to have an enhanced capacity for supporting their children (Blank & Werner-Lin, 2011; Haine et al., 2006; Lin, Sandler, Ayers, Wolchik, & Luecken, 2004).

Bereaved children and families may need professional support to cope with bereavement. In practice, there are many types of interventions for parentally bereaved children. These include support groups, group therapy, family therapy, and individual therapy, but most interventions have not been evaluated in research using a control group, follow-ups, or randomized controlled trials (Currier, Holland, & Neimeyer, 2007).
There is currently no consensus regarding what should be included in these interventions or how the potential effects should be measured, but most interventions seem to include a strong psychoeducational component (Currier et al., 2007). Two separate systematic reviews of interventions with parentally bereaved children have concluded that relatively brief interventions may prevent psychological health problems in children and adolescents as long as they are conducted at an early stage and target children at higher risk of developing problems (Bergman et al., 2017; Currier et al., 2007). Bergman et al. (2017) suggest that support programs where the family has joint sessions rather than separate parent and child groups are important, as this gives the family an opportunity to talk about the loss and their emotions; for some, this will be the first time they talk about it as a family.

One intervention for parentally bereaved children that stands out due to the promising results of randomized controlled trials and long-term follow-up is the Family Bereavement Program (FBP), which uses both psychoeducational and cognitive behavioral techniques (Ayers et al., 2014; Sandler et al., 2003, 2018). In designing the FBP, Sandler and colleagues created an empirically supported theoretical framework, used this framework to derive implications for program objectives, and designed an intervention model to accomplish these objectives (Sandler, Gersten, Reynolds, Kallgren, & Ramirez, 1988). The original model for the FBP specified several factors which mediated the effects of parental death on child symptomology, including parental demoralization, parental warmth, family cohesion, negative life events, stable positive events, family coping, discussion of grief-related issues, and satisfaction with social support (Sandler et al., 1992). Evaluation of the FBP using randomized controlled trials showed improved parenting skills, improved skills in coping with stress, improved mental health in parents and children, reductions in stressful events, and maintenance of family discussions on grief-related issues even at 6-year and 15-year follow-ups (Ayers et al., 2014; Sandler et al., 2003, 2018).

Despite the well-known consequences and risks for parentally bereaved children, and international efforts by organizations such as the National Alliance for Grieving Children in the US, The Irish Childhood Bereavement Network, and The Childhood Bereavement Network in the UK to establish standards of practice, there are no national standards of practice in Sweden regarding support and treatment for this group (Bergman & Hanson, 2014; Löwring, 2014). A Swedish report found that half of bereaved children felt that they had not received any support from their school or from the healthcare system, even though the child had felt that help and support were needed (Bergh Johannesson, Bondjers, Arnberg, Nilsson, Angarne-Lindberg, and Rostila, 2014).

Adapting the grief and communication family support intervention

The brief support intervention described here comprised three 90-min sessions where a parent and their child/children meet a family therapist together. This arrangement is in contrast to the original group-based format of the FBP where parent and child groups meet separately for 12 two-hour sessions (Ayers et al., 2014). The FBP covers many topics and skills, such as improving relationship quality, positive coping strategies, negative esteem and threat appraisals, adaptive control beliefs, adaptive emotional expression, positive parenting including communication skills, negative events, caregiver demoralization, and grief. Based on previous literature and discussion with the creator of the FBP, we chose to focus our intervention on grief and communication and have therefore adapted the grief or communication modules from the FBP to a family-based format. To achieve this goal, we combined the parent and child communication modules, which are meant to complement each other in a group format, so that they would work in a family format. Our intervention uses similar collaborative and active learning strategies as the FBP, such as modeling behavior, practicing new skills, and role-playing. Furthermore, emotional support is fostered by teaching parents and children effective skills for listening and expressing emotions, which are reviewed and practiced when negotiating and planning positive family activities (Sandler et al., 1988). Like the FBP, our Grief and Communication Family Support Intervention aims to reinforce open family communication, provide psychoeducation on grief, and promote healthy adaptation to bereavement.

The intervention was developed, after consultation with Irwin Sandler, the developer of the FBP, by a multi-disciplinary team including three family therapists, two psychology researchers, and two health care sciences researchers who were also registered nurses. This team had expertise in palliative care, bereavement care, and psychological interventions. The team met several times to discuss strategies for working with parentally bereaved families and to adapt and revise the communication focused modules included in the
treatment manual for the FBP. It was thought that a brief intervention consisting of three sessions, each 90 min long, conducted approximately 1 week apart, would be best suited to parentally bereaved families seeking support. This briefer format was considered to be more accessible for families with children and more feasible in the Swedish healthcare setting.

Inclusion and exclusion criteria were determined based on current literature and clinical experience. Families which had lost a parent at least 1 year ago due to illness and had children aged 3 years and older were eligible to be included. This timeline would give the family time to adjust to life without the deceased. The age limit of 3 years was established because most 3-year-old children are capable of expressing their thoughts and emotions and would be expected to be able to participate in the intervention even if in a somewhat limited capacity. To keep our sample as close to a realistic community setting as possible, there were no exclusion criteria for psychological or medical diagnosis or having sought support or therapy previously.

The therapists were instrumental in culturally adapting the FBP manual from an American context to a Swedish context by providing culturally relevant examples to include in the manual and adjusting the language to be less direct and more culturally appropriate. For example, “parents should” became “it could be helpful to try” and “families often struggle to talk about grief” became “sometimes it can be difficult to talk about grief.”

The intervention modules

Like the FBP, which aims to promote resilience in parentally bereaved children by influencing multiple risk and protective factors (Ayers et al., 2014), the main goal of the Grief and Communication Family Support Intervention is to improve communication between family members, especially with regards to their grief and speaking about the deceased parent. This is accomplished through psychoeducation, with the therapist providing information for the family about common grief reactions and communication strategies which can increase open communication. Cognitive behavioral methods, such as skills training and role-playing, are used in conjunction with family therapy methods which focus on family relationships and emotional processing through family discussion. The intervention offers modules focused on grief and communication which can be modified based on the ages of participating children.

**Session one**

The aims of session one are to establish a therapeutic alliance between the family and therapist, for the therapist to answer questions the family has about the intervention, and to clarify therapist and family member expectations. Session one focuses on providing the family with psychoeducation regarding grief and communication.

**Module 1: The family’s new circumstances.** The therapist should establish a therapeutic relationship/alliance and learn about the family’s situation, find out what the family would like to improve and what the family has been happy or unhappy with in their daily life, and learn more about their relationships and communication. This involves a semi-structured discussion, where each family member is encouraged to contribute their own experiences. It is also an opportunity for the therapist to observe family dynamics. Families discuss how their life and relationships were before the deceased parent became ill compared to how their life was during the parent’s illness and following the death including what types of psychological, somatic, or behavioral grief reactions they have experienced following the parent’s death.

**Module 2: Psychoeducation about grief.** The therapist provides the family with information about common grief reactions for preschool age children, school age children, adolescents, and adults using a brochure as a foundation. The brochure was developed by the research group and the family is encouraged to keep and review it at home. The therapist summarizes the important points of the brochure directly related to the family’s unique experiences. For example, if there are school aged children in the family, the therapist will focus on common grief reactions for school aged children and ask the family how that compares to their own experiences of grief.

**Module 3: Psychoeducation about 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. The family discusses these strategies and has the opportunity to ask questions.

**Module 4: Psychoeducation about what can make communication more or less difficult.** The parents and children are taught to identify barriers to good communication and to identify strategies which can ease communication in their family (e.g., not asking the parent for something or bringing up something important when the parent is on the phone or clearly busy with another task). The family is asked to generate examples from their own lives of what can make
communication more or less difficult. The therapist gives more examples or clarifies as necessary.

**Module 5: Summary of session one.** The therapist and family members summarize what was discussed and what the family members learned in the first session.

**Session two**

The aim of session two is to increase parent and child understanding of feelings and to practice using “I” messages and active listening to share thoughts and feelings. The goal is for parents and children to begin understanding that everyone hides their feelings sometimes, start being able to identify and talk about feelings, and discuss how certain behaviors can be helpful in one situation, but unhelpful in another.

**Module 1: Reflections from session one.** The therapist summarizes the previous session and family members can ask questions or give feedback.

**Module 2: Hiding feelings.** The family is asked to generate examples of feelings which people may generally try to hide, using feelings cards (i.e., pictures of teddy bears expressing different emotions) provided by the therapist. Family members then discuss why hiding feelings may be problematic. This discussion is conducted at a more general hypothetical level to avoid forcing family members to admit they have done something “wrong.” Situations where hiding one’s feelings may be appropriate or beneficial are also discussed.

**Module 3: Sharing positive feelings.** Parents and children are asked to identify feelings, talk about feelings, and to identify some positive effects of sharing feelings with each other. The family brainstorms about why people do not share positive feelings with each other. The family is then asked to give examples of how they could share positive feelings with each other and how this could impact them. The therapist explains how sharing positive feelings can be beneficial in a family. The idea behind this module, as taken from the FBP, is that teaching the family to share positive feelings will eventually make it easier and more comfortable for them to share all types of feelings.

**Module 4: “I” messages and active listening.** Family members learn to clearly and concisely express their thoughts and feelings using “I” messages through psychoeducation and practice these skills in a number of exercises led by the therapist. Active listening skills are taught to parents and children and practiced in role-playing exercises.

**Module 5: 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 about spending time together and brainstorm fun activities that they can do together. The family is asked to choose one of these activities to do, or at least plan, before session three. The goal of family time is to start building strong family relationships through planned activities which generate positive interactions between family members. This is also an opportunity for the family to have fun again and take a break from their grief.

**Module 6: Summary of session two.** The therapist and family members summarize what was discussed and what the family members learned in the second session. The family members are asked to bring a memento that reminds them of the deceased parent to share at the next session.

**Session three**

The aim of session three is to teach parents to help their children solve problems effectively using open communication. Furthermore, the family will practice the skills included in the previous sessions during the memento exercise.

**Module 1: Reflections from session two.** The therapist summarizes what was talked about in the previous session and families can ask questions or give feedback regarding session two. Families are also asked to tell the therapist how family time worked for them during the previous week.

**Module 2: Problem solving.** The therapist introduces a method for problem solving which the parent and children then practice using a problem which one of the children has recently had as an example.

**Module 3: Memento.** If an individual has forgotten their memento at home, they are given time and materials to draw a picture of it. Each person is given a turn to share their memento with the other family members and the therapist. Parents are asked to summarize what their children said about their mementos, thus 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 throughout the memento exercise.

**Module 4: Family discussion.** The family talks about their grief, including positive and negative changes which have occurred in the family since the parent’s death. The therapist should normalize these
changes and help the family see that they have the coping skills necessary to handle these changes. The family is asked to identify how their grief and/or communication may have changed during the intervention. The therapist should emphasize similarities and differences from the grief discussion in session one.

Module 5: Conclusion and summary of the intervention. Family members are asked to summarize what they have learned as well as what communication strategies they have 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.

Initial testing of the adapted intervention manual

The manual was tested with two parentally bereaved families to ensure all the modules would fit into the allotted time and to gain a better understanding of which modules worked well. Follow-up phone calls with the participating parents were conducted by the first author, 2 weeks after the final session. The study was registered at clinicaltrials.gov under the Unique Protocol ID: DRN 2016/1192/31/1 and was approved by the Regional Ethics Committee 2016/1192-31/1.

Setting

The intervention manual was tested in private family therapy clinics with the surviving parent and children present for all three sessions. Two families were recruited through the research group’s professional network, including participants from a previous interview study or clinical practice, and offered three sessions with a family therapist. Sessions were conducted approximately once a week during December 2017 and February 2018. Informed consent was obtained from the parents and informed assent was obtained from all children prior to participation.

Intervention fidelity

Adherence to the intervention manual (Chan, O’Neill, McKenzie, Love, & Kissane, 2004) was evaluated by audio-recording each session with the family’s permission and having the therapist complete an adherence checklist. The first author listened to the recorded sessions while completing an adherence checklist, which was then compared with the therapist’s completed adherence checklist to assess agreement between the therapist and first author. This process helped to determine if the therapist was able to follow the manual. Bereavement support competence (Chan et al., 2004) was ensured by using licensed family therapists with several years’ experience of working with grieving families. These were the same therapists who were involved in writing and developing the manual.

Participants

Family 1. Members were a father and two sons, ages 6 and 11 years. The children’s mother died from cancer 18 months prior to the intervention. The father had previously participated in the research group’s interview study, where he reported that his children avoided talking about their mother. The father was contacted by the research team to ask if he and his children would be interested in helping to test the adapted intervention manual. The father accepted and was put in contact with one of the three therapists. Approximately 1 week passed between each session.

Family 2. Members were a mother and her 7-year-old son. The father/husband had died 2 years previously. The mother spoke Swedish as her second language and sometimes struggled to understand the therapist. The therapist was able to adjust how she phrased her questions and responded to what the mother said to help clarify for the mother and prevent misunderstandings. The son was very shy but was engaged in the sessions and would answer the therapist’s questions by nodding yes or shaking his head no.

Case examples

The following case illustrates the components of the Grief and Communication Family Support Intervention, conducted in the initial test. The general structure of each session is described and followed by a description of how each family responded to the session.

Session one

The therapist began the first session by thanking the family for their interest in participating and clarifying the procedures of the research study. The therapist explained that the goal of the three sessions was to help the family have an easier time communicating with each other. She started by informing them that they would meet three times to talk about the family’s situation and grief and to try new communication strategies which the family might find useful. The
The therapist began by asking the family about their current situation as well as similarities and differences between their current situation and the family's situation before the parent became ill. While the family shared, the therapist normalized their experiences of grief and loss and validated their feelings.

As this discussion became more focused on feelings of grief, the therapist shared the grief brochure with the family and talked about normal grief reactions among children and adults. The parents took the brochure home to review it with their children. The therapist then provided the family with psycho-educative information on communication and situations which could promote or hinder communication.

While the therapist met with Family 1, the children asked their father questions about their mother and the family began to create a narrative together. The children shared what they remembered and the father elaborated to fill in some details for the therapist. The children stated that their father had become stricter since their mother died. The father said that the children might be correct and explained that he had been feeling quite a lot of stress due to both the practical and the emotional changes associated with his wife's illness and death. He promised the children to discuss this change further and to try to be less strict and more emotionally available. In contrast to the children from Family 1, the son from Family 2 was very shy and didn't want to speak. The therapist responded to the son's shyness by asking him more direct questions which he could answer by shaking his head no or nodding yes. She also engaged him by having him draw a picture of his family before his father died and drawing a picture of his family after his father died and asking questions about the drawings.

While the children from Family 1 were verbally participating by asking questions and discussing which grief reactions they could relate to, the son from Family 2 was very calm and reflective during the discussion of common grief reactions aided by the grief brochure. With Family 2, the therapist was concerned by the son's lack of response and asked him who he normally talks to about his father and he didn't answer. The mother responded that her son never talks to her about his deceased father. The family then set a goal to learn how to talk to each other about the son's father. This was followed by a discussion of how the mother and son usually communicate about every day topics. The therapist suggested a few strategies which may improve their communication such as the mother sharing her own thoughts and feelings to help the son feel more comfortable sharing his.

The children from Family 1 were surprised to learn that their father had a hard time listening to them when he was busy with other household tasks or talking on the phone and agreed to work with their father to establish better rules for communication at home. This session was closer to two hours with each family rather than 90 min. The younger son from Family 1 was not able to sit still for so long and the therapist chose to give the family a break in the middle of the session.

**Session two**

The session began with the therapist reviewing what the family had talked about during the first session and asking if they had any questions. The therapist then introduced the feelings cards which were used to assist the children in identifying feelings that people sometimes hide. The session continued with the therapist explaining "I" messages and demonstrating active listening. The session ended with the therapist explaining *Family Time* and discussing which activities the family liked to do together. The therapist explained that doing fun activities together was a good way to build strong family relationships and concluded the session by asking the family to bring mementos that reminded them of the deceased parent to the next session.

With some prompting from the therapist, the two children from Family 1 could share that they sometimes do not like to show that they are sad or upset. Their father explained that he does not like to show when he is worried and that sometimes his worry is expressed as anger or frustration. The therapist asked the children if they knew that their father worried about them, to which the children responded "no, he is an adult." This module seemed to help both the father and sons understand how feelings are sometimes hidden or masked as other feelings.

While conducting the module on hiding feelings with Family 2, the son was just as shy as he had been during the first session. The mother gave several examples of feelings she typically hides such as trying to hide her sadness and loneliness after her husband's death. The therapist validated that it was common for people to want to hide how sad they felt after someone dies possibly because they don't want to be a burden on others or make someone else upset. The therapist then used the feelings cards with both families to help them identify other feelings people may want to hide and talk about how they had been feeling. The son from Family 2 was very quiet during this
module and participated by choosing feeling cards for feeling shy and disappointed. The therapist and mother discussed reasons why people may want to hide their feelings and the son seemed to listen attentively.

In contrast, the children from Family 1 laughed and interacted with their father and the therapist while talking about feelings and acting out how they show feelings during the module *Sharing Positive Feelings*. The whole family was active and engaged and seemed to be having fun. The children from Family 1 and mother from Family 2 struggled with the module on “I”-messages but the father in Family 1 seemed to find it easy and useful. The module on active listening was easier for the children and parents, as the therapist explained what body language and eye contact were by acting out and role-playing what types of body language indicate if someone is listening or not.

The father from Family 1 expressed that spending time as a family doing fun activities was something he hoped they could prioritize more. He and his sons had an easy time discussing activities they would like to do together. Family 2 tried to identify some activities that both the mother and son enjoy. The son nodded yes or shook his head no to the various suggestions. The therapist used the son’s drawings from the first session to identify activities he used to do with his father that he could now do with his mother. Since the son was so quiet, the therapist gave him and his mother paper to write or draw what activities they would like to do together. The son became excited and started asking how to spell some of the activities he wanted to write down. They then compared their lists and saw that they both wanted to do the same activities.

This session fit within the planned 90 min. Although the younger son in Family 1 struggled to sit still, he did listen to the family discussions and commented on what his father and brother said. The older children were actively engaged throughout the session.

**Session three**

The therapist asked the family what they had done since the last session and what they remembered from the previous session. She then introduced a strategy for problem solving. The memento sharing exercise provided each family member with an opportunity to share memories of the deceased parent. Everyone used active listening during this exercise. The therapist concluded the final session by asking the family about their experiences of the intervention. The therapist reminded them that they could use whichever communication strategies they thought had worked best for them at home. She encouraged them to continue practicing the communication strategies and planning fun activities to do together. She then thanked the family for their participation.

The father from Family 1 said that since the previous session, the family had focused on spending time together doing fun activities like ice skating and baking cookies and stated that they had establishing family rules about when would be a good time to have important conversations and how to improve communication in the family. The mother and son from Family 2 had to cancel their plans for “Family Time” due to the mother’s work schedule.

The module on problem solving was omitted with Family 1 as neither child could come up with a problem or conflict that they wanted to share. During the problem-solving module with Family 2, the mother stated that one problem was that she can see her son has something to say to her but he isn’t brave enough to say it. The therapist asked her if she had ever asked her son why he was shy or uncomfortable speaking with people. She stated she had never asked. Her son sat next to her looking down while drinking a juice box. The therapist explained that sometimes children need an adult’s help to explain their thoughts or feelings and reminded the family about the strategies they had practiced in the previous sessions. The son explained some of the reasons he was afraid and the therapist encouraged him to tell his mother when he was scared and ask her for help. The mother further explained that her son does well in school academically and socially but at home he is very clingy and always wants to be close to her. The therapist explained that separation anxiety is common in children following a parent’s death and helped the mother to practice reassuring him without reinforcing his fear or dependence on her.

The younger son from Family 1 asked many questions about his mother and struggled to remember her accurately. His father answered his questions and provided more details and anecdotes about their mother, including how they had met and other aspects of their early relationship. This exercise resulted in a long discussion with Family 1 about the children’s memories and feelings. With Family 2, the son had his father’s old camera with him to share during the memento module. The mother had brought as her memento a photograph of her husband together with her son when he was only 10 days old.
She talked about how the photograph made her feel both happy and sad and that her husband had been her best friend upon whom she could always depend. The therapist thanked them both for sharing.

The therapist concluded the session by summarizing what the family had discussed in all three sessions and encouraged them to continue working on their communication. The father and children in Family 1 all said that the intervention provided as good opportunity to listen to one another and the father thought it had been very positive to have time together as a family just to talk. The mother in Family 2 excitedly stated that she thought her son was listening and sharing more.

**Follow-up telephone call**

One follow-up telephone call was conducted with each participating parent by the first author 2 weeks after the final session. Parents were asked what they thought of the sessions and if they had any suggestions for improvement. Both parents stated that having an opportunity to speak and share with their children in a safe and structured environment had been meaningful to them. They also reported that their children spoke more openly with them and asked more questions about the deceased parent following the intervention. When asked, neither parent offered suggestions for improving the intervention.

**Therapist adherence**

Examination of the completed adherence checklists and audio recordings of sessions indicated that the modules were not always completed exactly as planned and often took longer than expected, which signaled that modifications to the manual were needed.

**Discussion**

The therapists reported that it was easy to follow the manual and felt that the participating families responded well to each session. The evidence provided from testing the adapted manual with two families showed that the therapists were able to follow the manual without any major deviation. During follow-up phone call with each parent, the parents stated that the intervention had been useful and meaningful as it seemed to improve communication and family relationships. On the other hand, the sessions frequently took longer than intended as the therapists allowed family discussions to continue longer than anticipated, often at the expense of the skills training exercises.

As this intervention had never been tested and the research group felt the content of intervention manual was quite extensive, it was decided to do a test with only two families to allow the therapists to work with the manual and alter it before a larger pilot test was conducted. Having tested the intervention with only two families is a clear limitation but a positive trend for adherence, satisfaction, and subjective reports of improved communication and relationships in the families were found.

The advantages and disadvantages of each module were discussed and debated by the two therapists and the first author. Difficulties concerning the participating children’s ages and developmental levels as well as issues related to family dynamics in the two test families were discussed. We also proposed changes to the intervention, which were implemented in a subsequent study. To make the first session fit into the allotted 90 min, the introduction to “I” messages was removed, as this content was discussed and practiced in session two. Additionally, another change to session one was that *Psychoeducation about what can make communication more or less difficult*, because the latter addressed some barriers to communication, such as finding the right time to talk.

No changes were made to session two. The module on problem solving in session three seemed to put undue pressure on the children. Initially a step-by-step guide for problem solving involving a concrete skills training exercise, the module was condensed to provide a more general overview of problem-solving strategies and discussion with the family about what could be useful in their family. Focus was further shifted to a discussion of what types of problems would be appropriate for a child to solve on their own and when it would be appropriate or even necessary for a parent to help the child solve a problem.

During the revision process, it was decided that the exercises and role-play should be conducted more explicitly by the therapists rather than having a process-oriented discussion. Reasons for this included keeping younger children active and engaged, as well as allowing the family to practice the skills which were being taught.

One advantage of using a family context is that sessions may be easier to schedule than coordinating group sessions. However, a family context does not
provide families with the opportunity to exchange experiences with other bereaved families. As this intervention is brief and only comprised of three sessions, many families may need more support than what can be provided through this intervention alone. By starting with three sessions, therapists may be able to implement it in private practice, social service, hospital, hospice, or school settings and use it to assess how a family, or individual family members, are coping with their grief and recommend other supportive resources based on the family’s unique needs.

This study describes the many factors considered during the development of the Grief and Communication Support Intervention. The empirical evidence showing the effectiveness of the Family Bereavement Program was important when determining the focus of this intervention (Sandler et al., 2018). The therapeutic approach and structure were also considered in an attempt to ensure the intervention would be possible to implement. Trialing the intervention with two families provided initial data suggested that that the Grief and Communication Support Intervention could be feasible as well as beneficial to families following the death of a parent. The knowledge we developed was used to improve and streamline the manual, which is being tested in an exploratory pilot study using pre-post assessments to evaluate fidelity and identify potential effects of the intervention on psychological health and family communication. If the intervention is found to be feasible and effective, the manual may be further revised and tested in a larger randomized controlled trial. Further testing may result in a feasible, effective, manual-based support intervention which improves psychological health and communication in parentally bereaved families.

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The Grief and Communication Family Support Intervention: Intervention Fidelity, Participant Experiences, and Potential Outcomes

Abstract
This study aimed to evaluate intervention fidelity and explore participants’ experiences and potential outcomes after participating in the intervention. Using a pre-test 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 post-intervention 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.

Keywords: Children; Adolescents; Death of a parent; Counseling; Bereavement

The Grief and Communication Family Support Intervention: Intervention Fidelity, Participant Experiences, and Potential Outcomes

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 post-traumatic 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, Kriecbergs, & 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 self-harm 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, including 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 non-profit 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 mild-moderate 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-minute 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 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 pre-test 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 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 e-mail. 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 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 and 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 comprised demographics, questions about care, and family-related 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 in a parent questionnaire about their own experiences, as well as 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 a questionnaire for themselves and one for each child. Post-intervention assessment via online questionnaire occurred twice: 1 month and 6 months post-intervention.

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 minutes long. When children or adolescents were included in the interview, the family was interviewed together, with the final 15–20 minutes 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 user-friendly 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 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’ self-report 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 from 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 minutes for all families and that session three was shorter than 90 minutes 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 minutes, 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 follow-up 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 minutes 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.

**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 follow-up 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 14-year-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 to explain.

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.

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 when 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 to the NIH BCC guidelines. 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 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 re-establish 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 as 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.

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.

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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.

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**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 each other.

*"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.

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**Session 3**

*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.
Table 2

*Parent Demographic Characteristics (n = 10)*

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

*Child Demographic Characteristics (n = 14)*

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

Table 4

*Treatment Adherence – Number of Modules Completed*

<table>
<thead>
<tr>
<th>Family</th>
<th>Session 1: 5 Modules</th>
<th>Session 2: 6 Modules</th>
<th>Session 3: 5 Modules</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Therapist report</td>
<td>Audio recording</td>
<td>Therapist report</td>
</tr>
<tr>
<td>1</td>
<td>5</td>
<td>4</td>
<td>Not completed</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
<td>Not recorded</td>
<td>6</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>6</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>8</td>
<td>4</td>
<td>Not recorded</td>
<td>Only participated in</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>session 1</td>
</tr>
<tr>
<td>9</td>
<td>5</td>
<td>5</td>
<td>Only participated in</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>session 1</td>
</tr>
<tr>
<td>10</td>
<td>5</td>
<td>Not recorded</td>
<td>5</td>
</tr>
<tr>
<td>Average score</td>
<td>4.8/5</td>
<td>4.2/5</td>
<td>4.7/6</td>
</tr>
</tbody>
</table>
Table 5

Responses to the question “During the session did you/your child receive information regarding…”

<table>
<thead>
<tr>
<th></th>
<th>Parents (n = 7)</th>
<th>Children (n = 9)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
<td>Some</td>
</tr>
<tr>
<td>What grief is</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Common grief reactions for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yourself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Common grief reactions for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem-solving</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication strategies</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 6

Responses to the question “During the session did you/your child have the opportunity to practice…”

<table>
<thead>
<tr>
<th></th>
<th>Parents (n = 7)</th>
<th>Children (n = 9)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
<td>Some</td>
</tr>
<tr>
<td>Identifying your own grief</td>
<td></td>
<td></td>
</tr>
<tr>
<td>reactions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identifying other family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>members’ grief reactions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Processing your emotions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talking about the grief you</td>
<td></td>
<td></td>
</tr>
<tr>
<td>feel</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sharing feelings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Solving problems in a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>positive way</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using communication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>strategies such as active</td>
<td></td>
<td></td>
</tr>
<tr>
<td>listening or “I” messages</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 7

Responses to the question “Do you use any of the strategies included in the three sessions in your family today?”

<table>
<thead>
<tr>
<th></th>
<th>Parents (n = 7)</th>
<th></th>
<th>Children (n = 9)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
<td>Very</td>
</tr>
<tr>
<td>Identifying your own grief reactions</td>
<td>0</td>
<td>7</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Identifying other family members’ grief reactions</td>
<td>1</td>
<td>5</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Processing your emotions</td>
<td>0</td>
<td>4</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Talking about the grief you feel</td>
<td>0</td>
<td>4</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Sharing feelings</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Problem-solving</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Active listening</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>“I” messages</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>0</td>
</tr>
</tbody>
</table>
Development and Evaluation of the Grief and Communication Family Support Intervention for Parentally Bereaved Families in Sweden

Ersta Sköndal Bräcke University College has third-cycle courses and a PhD programme within the field The Individual in the Welfare Society, with currently two third-cycle subject areas, Palliative care and Social welfare and the civil society. The area frames a field of knowledge in which both the individual in palliative care and social welfare as well as societal interests and conditions are accommodated.

Megan Falk received her Bachelor of Psychology from San Francisco State University in 2008. After moving to Sweden in 2010 she focused on learning the Swedish language before completing her Master of Social Science in Psychology with an emphasis in cognitive behavioral therapy. Megan has many years of experience working with children, adolescents, and families in crisis at residential treatment centers and as a school counselor. Her PhD project focused on the development and evaluation of a psycho-social support intervention for families following a parent’s death from cancer.